THE UNIVERSITY OF ALBERTA

SORROW OR COMMITMENT; A PHENOMENOLOGICAL STUDY OF THE EXPERIENCE OF BEING THE PARENTS OF A DEPENDENT HANDICAPPED CHILD

by

BRUCE VICTOR ADAMS

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IN

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Sorrow or Commitment; A Phenomenological Study of the Experience of Being the Parents of a Dependent Handicapped Child submitted by Bruce Victor ADAMS in partial fulfulment of the requirements for the degree of Master of Education in Educational Psychology (Counselling).

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Abstract

The purpose of this study was to understand, and learn from the experiences of the parents of dependent handicapped children. A phenomenological methodology was utilized and is compatible with the goal of exploring the experience articulated by the parents interviewed. Eighteen men and women participated in the study, and all were parents of dependent handicapped children attending school programs. Husbands and wives were interviewed together where applicable, and in total 10 interviews took place. Five themes emerged from the data analysis process applied to the raw description provided by the parents. The themes were as follows:

1. predominant influence on the mother's "life-world";
2. very strong feelings about the type and quality of assistance received from social agencies and professionals;
3. deep concern about the future of their dependent handicapped child;
4. ongoing stress and anxiety;
5. influence of the dependent handicapped child on other family members.

The implications of the study were reviewed and recommendations made for an increased level of practical assistance to parents, and improvements in the parent-professional relationship.

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Chapter I

Introduction

This thesis is an exploration of the meaning of the experience of parenting a dependent, or severely multiple handicapped child from the point of view of the parents. Aspects that will be examined include how these men and women perceive the parenting of their dependent handicapped child in relationship to their own lives, and the difficulties and satisfactions they have encountered as parents over a period of time. The goal of this thesis is to present a description, that is as accurate as possible, of what it is like to be the parent of a dependent handicapped child. A phenomenological research method was chosen because it appears to be the most compatible with the research goal. Giorgi (1971a) defined phenomenology as "the study of phenomena as experienced by man with an emphasis on the phenomenon itself exactly as it reveals itself to the experiencing individual in all its concreteness and particularity" (p. 11). If the "phenomenon" is thought of as parenting a dependent handicapped child, and the "experiencing individuals" as the parents themselves, then there is a very close match between Giorgi's concept of phenomenology and the goal of this thesis.

There are reasons why a study of the self-perceived experience of the parents of dependent

handicapped children may have some importance at this time. First of all, several authors (e.g., Bell, 1968; Clark-Stewart, 1979; Gallagher, Beckman & Cross, 1983) have pointed out that professionals trying to help the families of handicapped children are often faced with limitations of understanding and knowledge about the topic. Gallagher et al. suggested that a reason for this limitation of knowledge is that the family itself is a fairly recent subject of investigation. Research about the family has only burgeoned in the last ten years and this is mainly through the efforts of counselors and psychotherapists. It is primarily special education personnel, however, who deal with the parents of handicapped children and among this group there may be a lack of awareness of research on the family, or uncertainty about the specific applicability of family research to families with handicapped children. Obtaining more information about the experience of families of handicapped children would seem to be appropriate at this time, as a contribution to the understanding of the parents of mentally handicapped children, and hence, the building of better cooperation between parents and professionals.

A second reason why a thesis such as this may have some importance at this time, relates to the point in the history of the treatment of the mentally

handicapped at which today's parents find themselves. As the historical review will point out, today's parents of handicapped children live in an age in which non-institutionalization and normalization (Wolfensberger, 1972) are the trends (at least in North America). This fact, combined with today's advanced life-saving medical techniques, has meant that greater numbers of more severely physically and mentally handicapped children are remaining with their parents. Greater numbers of dependent handicapped children living at home raises the issue of the effects of this on the parents. In fact, a great number of questions can be raised about this trend. Do the more severely handicapped children now living with their parents have a strong impact on the parents? Is the impact of the dependent handicapped child on the parents primarily negative or positive? Is it possible that the positive effects of non-institutionalization and normalization have been offset by increased pressure on the parents of mentally handicapped children caused by the resulting increased parent responsibilities for the handicapped child? Obviously, conclusive answers to such important questions as these are beyond the scope of this thesis. The literature review, however, will suggest that most current research related to the topic may not be leading towards eventual answers to the

above questions. This is because most current research deals with the factors that influence the experience of the parents of handicapped children, instead of the content of the experience itself. It is the perspective of this study that the best way to understand the experience of the parents of dependent handicapped children is to ask them about it. Phenomenology merely provides a system for explicating and thematicizing description given by the parents. It is hoped that continued phenomenological research about the parenting of handicapped children will lead to an improved understanding of what the increasingly common experience of living with a mentally handicapped child in the family is like on a day-to-day basis.

Background to the Study

In this section, additional background information about the range of characteristics of dependent handicapped children, difficulties in using the term, "dependent handicapped", and the historical context that these individuals and their parents operate within, will be dealt with.

Dependent Handicapped Children.

The term "dependent handicapped" is used by the Alberta Government Department of Education (e.g. Alberta Education, 1983), and generally refers to that group of children within the most severe category of

mental handicap, and the least degree of adaptive behaviour, as grouped together in Alberta schools.

The 1983 curriculum guide for the dependent handicapped published by the Alberta Government Department of Education describes dependent handicapped students in the following way:

> Even though dependent handicapped students vary greatly in skills and abilities, they tend to have some common characteristics. They are generally severely and profoundly mentally handicapped, have numerous and often severe physical disabilities, lack the ability to guard themselves against common dangers, and may need the support of others for life. Some students may be dependent handicapped because of physical or medical needs, yet be functioning cognitively above the severe-to-profound level of mental handicap. From an educational perspective, these students share the characteristics of functional retardation in significant and individual ways. As such, each requires remedial and developmental instruction (p.iv).

The dependent handicapped group is distinguishable from the trainable mentally handicapped (in Canadian education) in that the trainable group can obtain a reasonable degree of self-sufficiency as adults, while

the dependent handicapped group is expected to remain fairly dependent on close assistance throughout their lives. Although some of these individuals have little in the way of physical impairment, a majority are multiply handicapped which implies a variety of physical impairments that further limit their degree of independent functioning. The dependent handicapped often have neurological impairments such as cerebral palsy or convulsive disorders in addition, and related to their intellectual retardation (Hallahan & Kauffman, 1982). Similarly, severe deficits across a variety of functioning areas such as motor development, speech and language, visual and auditory functioning, and adaptive behavior occur frequently (Heward & Orlansky, 1984). No specific set of behaviors are common to all dependent handicapped children, but they frequently display behavior associated with limited communication; delayed development; frequently inappropriate, ritualistic, or self-stimulatory behavior; deficits in self-help skills; and infrequent constructive behavior and interaction (Guess & Mulligan, 1982). Generally, the dependent handicapped are the most varied of all retarded groups, partly because of the great range of motor, sensory, and medical problems they can have, and partly because of the diverse effects that specific types of neurological impairment can have on behavior.

This group has also been the most frequently institutionalized, and as they begin to profit from the fairly recent application of structured programming, we are only now beginning to recognize their potential for learning (Snell, 1983).

In addition to the preceding description of the range of characteristics of the dependent handicapped, there remains a need to further clarify the term, "dependent handicapped" itself, in relationship to the parameters and context of its usage. First of all, it should be noted that "dependent handicapped" is primarily a Canadian term. In the United States, educators may use classifications such as "educable mentally retarded" or "trainable mentally retarded", and usually the latter group excludes the lower functioning "profoundly mentally retarded" (Hallahan & Kauffman, 1982, p. 43). Until fairly recently American educators referred to the profoundly mentally retarded as "custodial mentally retarded", although currently there appears to be some confusion about the proper label for this population (Robinson & Robinson, 1976).

According to Hallahan & Kauffman, the trainable mentally retarded (T.M.R.) would include students with I.Q. scores between approximately 50 and approximately 25, while the profoundly (or custodial) retarded group would fall below this level. Roughly, the trainable

mentally retarded group would correspond to the "moderate" and "severe" catagories on the American Association on Mental Deficiency Adaptive Behavior Scale, while the profound or custodial groups are similarly catagorized by American educators and the American Association on Mental Deficiency system. Alberta Education (1982) suggests that pupils enrolled in their dependent handicapped classes should:

> a) have a functioning intelligence quotient below 30 and/or be so physically incapacitated that he/she cannot profit from a structured program for the trainable mentally handicapped;
>
> b) have an adaptive behavior score equivalent to the profoundly retarded level on an adaptive behavior scale, e.g. American Association on Mental Deficiency Adaptive Scale, Progress Assessment Chart, Vineland. (p. 2)

It would appear, therefore, that students in Canadian dependent handicapped programs more closely resemble the American profoundly retarded than the American trainable mentally retarded. The Canadian parameters even make reference to the profound catagory on the American Association on Mental Deficiency Adapative Behavior Scale as part of the selection process criteria.

Certainly there appears to be a difference between American trainable mentally retarded curriculums and the Alberta dependent handicapped curriculum. While the former includes an emphasis on functional academics and vocational skills (Snell, 1983), the dependent handicapped program emphasizes "socialization, communication, concepts formation, motor skills, self-care, purposeful activity, and community skill" (Alberta Education, 1983, p. 245). It seems probable that this difference is a reflection of the essentially different populations served.

On the other hand, both quotations from Alberta Education presented in this section suggest that dependent handicapped classrooms in Alberta frequently contain somewhat higher intellectually functioning individuals in cases where the student has a high degree of physical incapacitation. The author of this thesis has interacted with a number of very physically incapacitated students with intellectual functioning well above the profound level, in dependent handicapped classes in Edmonton and Fort McMurray. Some of the parents interviewed for this thesis also felt that their severely physically incapacitated child was only moderately, as opposed to severely, retarded. Although it appears that dependent handicapped children most frequently correspond to the American profoundly

retarded, it appears that some of the more physically incapacitated dependent handicapped group could be candidates for trainable mentally retarded programming in the United States.

A second important point that should be noted about the term "dependent handicapped" is that it represents an educational catagory. Thus, the term "dependent handicapped" is seldom used by professionals involved in assessment of children but not directly with the child's educational placement group. For example, psychologists and other users of the various assessment devices such as intelligence and adaptive behavior scales, most frequently use the catagories suggested by the test being employed as opposed to a term like "dependent handicapped". In addition, medical professionals often focus on the particular syndrome or brain dysfunction of the child when they are describing or catagorizing the mentally handicapped child. Neither of these groups would be likely to use the term, "dependent handicapped" or any educational placement category or terminology.

Thus, since "dependent handicapped" is an educational category, this suggests that the parameters for the inclusion of any student in this catagory are also educational; and thus, there is an emphasis on the degree of "functional retardation" (Alberta Education,

1983, p. iv) in the selection of students for this group. The teaching of "functional skills" has recently become very much the focus of educational programs for the mentally handicapped in North America (Alberta Education, 1983; Snell, 1983). "A functional skill is one that is frequently demanded in a student's natural environment" (Heward & Orlansky, 1984, p. 340). Thus, tooth brushing is functional while "pegboarding" is not. Factors that have little to do with intelligence such as severe behavior disorder or severe physical impairment can often greatly affect functionality. As a result, if it appears that educators are moving towards "functional retardation" as a central criteria in program placement, then, obviously, they are going to find greater diversity in the intelligence levels of students in groups such as the dependent handicapped.

Ultimately, it appears that for a variety of reasons discussed here, the dependent handicapped may be a very diverse group of children indeed. Perhaps the most essential reason for the diversity of this group is that it is represented by an essentially exclusionary definition. The dependent handicapped are a group made up of all students who are not served by other educational programs. From the perspective of the experience of their parents, however, all dependent

handicapped children share one very important characteristic. The low functional skills of the group mean that the care-giving demands on their parents are extremely high. Moreover, the care-giving demands presented by the dependent handicapped group often increase with the child's age (due to increased size and weight), instead of decreasing with age, as they usually do for other children.

There remains the problem of answering why the term, "dependent handicapped" was chosen for use in the thesis in view of the problems with limited usage and uncertain parameters it has been suggested that the term represents. The term, "dependent handicapped" was retained because the parents interviewed for this thesis used it to refer to their handicapped childrens' condition. They were most familiar with this term because their child attended a dependent handicapped class, and the teachers and teachers aides they came into contact with also used the term to refer to the condition of the child. It was felt that it would be unfair to the parents to use different terminology that may seem unfamiliar or even pejorative to them with reference to their mentally handicapped child.

The Historical Context.

Any effort to describe and understand the experience of the parents of mentally handicapped

children should not ignore the historical context within which the parents are functioning. The goal of this section will be to highlight how the experience of the parents of the mentally handicapped is inter-related with the historical-social context in which the experience is taking place. Hopefully, this will also contribute to an explanation of why the continued examination of the experience of the parents of dependent handicapped children is especially important at this point in history. Rather than compiling a history of the treatment of the mentally retarded, the above goal may best be accomplished by contrasting the historical-social context facing today's parents of the mentally retarded, with that facing such parents in an earlier era, using for comparative purposes the period between 1900 and 1920, which many American historians have referred to as the "Progressive Era" (Scheerenberger, 1983, p. 137).

Sheenrenberger (1983) has suggested that the "Progressive Era" was progressive because a large group of middle-class moralists known as "progressives" were able to institute a great number of reforms which eliminated many of the extreme social ills in society at the time. In the field of mental retardation, however, many "progressive" experts (e.g. Barr, 1904; Fernald, 1912; Goddard, 1912, 1920) believed that

heredity was the prime etiological factor associated with mental retardation. They also believed that "feeblemindedness" was the source of many social ills. As a result, many of these same experts advocated that society be protected from the mentally handicapped and their potential offspring, by controlling and segregating them through institutionalization and/or sterilizing them (Scheerenberger, 1983). As Rothman (1978) has suggested:

> Progressives' sense of paternalism enabled them to move in harsh and stringent ways against those that they believed to be irreformable and beyond rehabilitation--namely, the recidivist, the defective and the mentally retarded...Accordingly, many Progressives accepted the eugenic arguments of the time and were eager to confine the retarded for life, particularly the borderline retarded who might pass as normal and so go on to propagate a race of defectives. Some Progressives were also ready to sterilize the retarded, or make that operation the prerequisite for release into the community. (p. 81-82)

Such attitudes may seem archaic and unfortunate to modern ears, but we should remember that they were considered to be in the forefront of thought at the time. Such attitudes may also be a good example of the

way research and expert testimony can provide "objectivity" for what society wants to hear. One might wonder if today's research and attitude trends will seem as archaic and unfortunate 70 years from now if another dramatic attitude and practice shift takes place. Obviously, the experience of the parents of the mentally handicapped during the "Progressive Era" would have been strongly affected by the attitudes of their time, just as today's parents are influenced by today's attitudes.

One of the long standing legacies of the "Progressive" and earlier eras was that mentally handicapped individuals usually spent their lives in large institutions. This trend only began to change in the late 1960's when deinstitutionalization and normalization (Wolfensberger, 1972) became popular and were translated into social policy. School boards across the country now frequently provide programs for all levels of mentally handicapped students, often in regular program schools. Another result of recent trends has been that many more dependent handicapped children are remaining in the home with their parents since this is the most normalized situation for them. This latter trend represents a very dramatic shift, in view of the earlier statement that the dependent handicapped have previously been routinely

institutionalized and were the most frequently institutionalized retarded group (Snell, 1983). Certainly the sudden increase in numbers of such low-functioning, high care-demanding individuals in family homes suggests a unique and influential phenomenon worthy of the type of investigation illustrated in this thesis.

Parent organizations promoting the benefits of integration and normalization have had an increased impact on parents in recent years. For example, Pivato (1984) has made reference to a "usual Gateway pep-talk" (p. 124) concerning the benefits of normalization and integration that an Edmonton parent organization (called Gateway) uses when dealing with the parents of mentally handicapped children early in their child's life. Essentially, the "pep-talk" represents the beginning of a series of steps provided by Gateway, which assists parents towards accepting and participating in a more normalized and integrated lifestyle for their mentally handicapped child. Such parent organizations often provide a system for allowing parents to make their own feelings and opinions heard, as well as a vehicle for disseminating accepted principles and practices, such as normalization and integration, among new parents of the mentally handicapped. It will be interesting when

looking at the results of this thesis to see if the principles of current trends such as normalization are reflected in the co-researchers' feelings and experience as a result of the influence of organizations such as Gateway. If it is true that historical-social trends are often a reaction to previous ones (Commager, 1966) then perhaps strong negative feelings about previous trends (e.g. institutionalization) may also be evident in the attitudes of "co-researchers" or participants in this thesis.

As will be explained on page 47 of this thesis, a major goal of the thesis is to seek an intersubjective meaning of the phenomenon, and it is therefore important to look at both the experience of the individual and the historical context in which such experiences are taking place. In this section it has been pointed out how the historical context in which the parents of handicapped children find themselves may greatly affect their experience and their attitude. Certainly it seems unlikely that a phenomenological study such as this one would have had similar results 30 years ago. For one thing, although not all parents followed the trend toward institutionalization, it would certainly have been more difficult to find dependent handicapped children living with their

families at that time. Certainly the experience of today's parents of the dependent handicapped will be greatly intertwined with the influence of current and perhaps past trends in dealing with the mentally handicapped and their parents. In addition, because the trend toward in-home parenting of the dependent handicapped is a fairly recent phenomenon, the further investigation of this phenomenon at this time is clearly necessary. Society should know what it is like to deal with a dependent handicapped child, as a parent, day after day; otherwise, we will have little hope of understanding or helping these parents in relationship to their true needs.

Definition of Terms

bracketing - the clarification and setting aside of the researcher's own preconceptions so they do not impinge on the explication of the themes and structure in the co-researcher's descriptions (Becker, 1986; Polkinghorne, 1981a).

co-researchers - refers to the parents of dependent handicapped children who were interviewed for this study; this term is preferred over terms like "subjects" because the co-researchers actively participate in their contribution to the results, unlike the "subjects" in quantitative research

experiments who merely respond to the influence of controlled variables (Polkinghorne, 1983).

dependent handicapped - is a term used by the Alberta Department of Education to identify individuals within the established school program for those children who have the least degree of adaptive behaviour and the greatest extent of mental retardation (Alberta Education, 1982, 1983).

intuiting - eidetic intuiting is a method of bringing the essential meanings contained in raw description to a self-showing (Aanstoos, 1985), and it is illustrated in this thesis by the six steps for dealing with raw description as quoted from Colaizzi (1978).

life-world - this phenomenological concept suggests the individual experience and the world in which it takes place are actually an interwoven whole that should be treated as a single unit (Valle & King, 1978), or you could say the life-world is "the world as we live it prior to any reflection upon it as such" (Giorgi, 1970, p. 134).

paradigm - a methodological model defined by an implicit or explicit set of assumptions (Giorgi, 1970).

phenomena - data of human consciousness; objects, events, people, as experienced through human consciousness (Giorgi, 1970).

phenomenological research - a type of research which "seeks to develop presuppositionless, structural descriptions of what is given in experience. It uses specific methods designed to direct attention to what is given in human experience, to free the researcher from prejudgments about the data, and to bring to view the structural components through which experience is formed" (Polkinghorne, 1981a, p. 4).

phenomenology - "the study of phenomena as experienced by man with an emphasis on the phenomenon itself exactly as it reveals itself to the experiencing individual in all its concreteness and particularity" (Giorgi, 1971a, p. 11).

reduction - a process by which the raw descriptive data provided by co-researchers is gradually reduced of its non-essential details until the essential meanings of the life-worlds are revealed (Giorgi, 1985; Valle & King, 1978).

Chapter II

A Review of Related Literature

Earlier it was stated that professionals often face a lack of information about how to deal with the families of mentally handicapped children (Gallagher et al., 1983). This does not imply a lack of research related to the families of the mentally handicapped, however, because research studies related to this topic are quite abundant. We shall see later that it may be more the type of research currently done than the quantity of it which has contributed to the information shortage problem identified by Gallagher et al. At this point in the thesis it would be appropriate to review the research relevant to the topic. For the sake of convenience and explanation, the research will be reviewed under these three broad catagories; the quantitative research, the research based on stage theories, and other qualitative research. The goals of this section will be to provide some background with regard to other research closely related to the thesis topic, and to stress the limitation of the above catagories of research which would indicate the need for a phenomenological study such as this one.

The Quantitative Research

We can characterize the quantitative research as that which attempts to measure the influence of specific factors or variables that pertain to the

parents of mentally handicapped children. Such an approach is quite compatible with the cause and effect or correlational goals of the quantitative research paradigm. Certainly this type of research has contributed a great deal of information within its category. For example, in a review of literature related to the measurement of factors contributing to stress in families of the mentally handicapped, Gallagher et al. (1983) lists 67 separate studies related to this area alone.

In an attempt to select the research most relevant to this thesis, it first of all would seem appropriate to review the literature which is specifically related to the effects of dependent handicapped children on parents. Because "dependent handicapped" is mainly a local term, as was discussed earlier, this literature review relates to research connected with the severely, profoundly, or multiple handicapped or retarded. There are quite a number of studies in this catagory as well, but many of these are only indirectly related to the thesis topic. For example, Tallman (1965) reported that fathers have more difficulty coping with their mentally handicapped child in terms of the social stigma than do mothers (Gallager et al. p.13). Such a study is somewhat relevant; however, in the thesis, there is no attempt to distinguish among the types of

catagories of parents according to their reactions to their mentally handicapped child. Instead, the thesis will attempt to characterize the common experience of the parents of dependent handicapped children as a whole. As a result, greater importance should be given to quantitative studies which treat the catagory or severity of the handicapping as the independent variable, as opposed to studies which seek to measure variance relative to parental characteristics.

If there are quantitative studies which contribute to the notion that reactions among parents significantly vary according to the severity of the child's handicapping condition, then such studies would support any potential results of this thesis which might suggest that the parenting of specifically dependent handicapped children is an important and separate phenomenon. In other words, because the dependent handicapped are generally at the low extreme with regard to functionality and intelligence, then studies which support the notion that some important variable (e.g. parent stress) increases as a result of the reduced functioning or high-care demands of the child would also support the notion that the dependent handicapped do indeed have a very significant and unique impact on their parents. The key word in the above statement is "support", thus the above statement

does not imply an attempt to justify this thesis with quantitative evidence. It is the opinion of this thesis researcher, however, that the cause and effect relationships established by quantitative research can provide the phenomenological researcher with some guidance as to which phenomena are important enough to study in the first place, especially in terms of social need or importance.

In fact, there is a fair amount of research which suggests that parent difficulties increase with the lower functionality and higher care-giving demands that are features of the dependent handicapped group. For example, Beckman-Bell (1980) reported that 66% of the variance in parent and family problems could be accounted for by the number of additional or unusual care-giving demands presented by the mentally handicapped child alone. Similarily, Bristol (1979) found that the number of problems reported by mothers of the mentally handicapped were significantly contributed to by the degree of dependency and physical incapacitation exhibited by the mentally handicapped child. Moreover, in the study by Tallman (1965), mentioned earlier, results also showed that the acceptance and adaptation of the family of the mentally handicapped child is strongly deterred by increased visibility of the handicapped child. By "visibility",

Tallman appears to mean the unusual appearance and low functionality of the child in social situations, which are most characteristic of the dependent handicapped group. Also, with regard to the presence of "emotional disturbance" in parents, Tew and Laurence (1975) used a "Malaise Inventory" (Brodman, 1952), to conclude that there is a positive correlation between the degree of the child's disablement and the degree of "malaise" or "emotional disturbance" in his/her parents. In a similar vein, Butler, Gill and Pomeroy (1976) found that the mothers of children with more severe mental and physical handicaps tended to suffer greater isolation and restrictions of mobility than the mothers of more moderate handicapped groups. In addition to restricting physical mobility, there is even research to suggest that the presence of more severely mentally handicapped children in families, more frequently deters the families' potential for upward social mobility (Culver, 1967).

A most interesting study, which is also suggestive of causal significance dependent on the degree of the child's mental/physical handicap, was conducted by Fotheringham, Skelton and Hoddinott (1972). This research used an interview method of family functioning and was actually designed to compare families of retarded children who were institutionalized with the

families of children who remained at home. The results, however, suggested that while lower levels of the child's intellectual functioning were unrelated to the families' functioning for institutionalized children, there was a positive correlation between low levels of family functioning and lower levels in the child's intellectual development for children who remained at home. This finding not only supports evidence of the comparatively greater impact of the dependent handicapped on parents, but also supports the decision in this research to only study the parents of dependent handicapped children living at home. As suggested in the research procedure section, the parents of institutionalized children were excluded because it was presumed that their experience would represent a very different phenomenon.

Up to this point, a variety of studies suggesting that the dependent handicapped may have a greater impact on their parents than less severe groups, have been examined. Of course, it could be argued that most of the studies referred to are correlational in nature as opposed to ones demonstrating a clear cause-and-effect relationship. However, the tendency in quantitative research reviews is to propose the probability of a cause-and-effect relationship if enough correlational studies are pointing in a similar

direction. Indeed, this is what Gallagher et al. (1983) did when, based on similar research, they concluded that the degree of handicapping condition is a very significant factor influencing parents. This section has also suggested that the degree of handicapping condition may have a significant effect on a variety of parenting related areas including family problems, acceptance and adaptation, emotional disturbance, isolation and physical mobility, upward social mobility, and family functioning.

In addition to the above type of quantitative research, one other area of research has a very important relationship to this thesis topic. As stressed in the historical review, the experience of parents is very much interwoven with social trends, as they interact with society relating to their mentally handicapped child. As a result, it would be important to examine what the quantitative research has to say about the significance of various societal influences on the parents of the mentally handicapped. Possibly the two main contacts that parents have with society relating to their handicapped child are those associated with the child's educational program and other professionals who provide diagnosis or special assistance.

Gallagher et al. (1983) have suggested that, to a much greater extent than the parents of normal children, the parents of exceptional children spend significant amounts of time interacting with professionals. A variety of studies (Bricklin, 1970; Dembo, 1969; Moos, 1976; Turnbull, 1978b) have suggested that there are often significant problems in parent-professional relationships and they frequently appear to have a more negative than positive effect on parents in spite of good intentions by both parties.

With regard to relationships between parents and their mentally handicapped child's school program, Turnbull and Blacher-Dixon (1980) have reviewed a good deal of the literature related to parent-school interaction. In addition to revealing frequent conflict between educators and parents, as well these authors raised some particular concerns with regard to the effect that recent trends towards deinstitutionalization and least restrictive environments may be having on parents. Their conclusions suggest that the parents of mentally handicapped children may encounter several important additional difficulties when they have their child "mainstreamed" or placed in a setting with normal children. For example, they may:

1. face a daily reminder of the discrepancy between their child and the normal children around them;
2. share the "stigma" of handicap with their child and may not feel respected or accepted by other parents;
3. reveal a lack of interests in common with other parents;
4. be deeply concerned with the difficult social adjustment of their handicapped child;
5. worry that the normal school setting may lack the supportive services available when the program is focused on the handicapped (Gallagher et al., 1983, p. 14).

It will be interesting to see if any of the above concerns are reflected in themes of the thesis, as will be discussed.

In summary, we have dealt with quantitative research which relates to social factors influencing the parents of the mentally handicapped because it was felt that these studies may be reflected in parent discussion about their experience, the crux of this thesis. Also, there has been an effort to deal with the significance of the impact of more severely mentally handicapped children compared to more moderately handicapped groups. Support in the

quantitative research appears to exist for the treatment of the experience of the parents of the dependent handicapped children as a separate phenomenon. Although there appears to be a causal relationship between low functionality (hence, high care-giving demands) presented by children and the increased problems of their parents, there is not much conclusive literature concerning the ongoing details of the parents' experience which illustrates this causal relationship. It is hoped that a phenomenological study will be able to reveal the experiential content of the most important coping difficulties that parents of low functioning children have, as indicated by quantitative research studies. Phenomenological approaches may be preferable to other qualitative approaches because the former use a systematized method and paradigm for accessing the life-world (Giorgi, 1970) of the participants and this may be lacking in many other qualitative approaches (Polkinghorne, 1983). Both the phenomenological paradigm and the method stemming from it will be examined in Chapter Three.

Finally, it should be noted that very little quantitative research about any potentially positive effects of dependent handicapped children on their parents appears to exist (Wilkin, 1979). Perhaps

positive themes will also be identified using a phenomenological approach.

In addition to the preceding statements about the benefits of a phenomenological approach, there remains a need to suggest why further quantitative research would not eventually reveal everything we would want to know about the experience of the parents of the dependent handicapped. Why is a switch to phenomenological research so necessary? The obvious answer could be that quantitative research does not lead to a description of the actual experience, however, this is not entirely true. The accumulated results of quantitative research can be used to describe a phenomenon in terms of its experiential content. For example, Robinson and Robinson (1976) have put together a chapter in their book on the mentally retarded child, which describes the problems faced by the families of the mentally retarded (p. 413-432). The description is based on a compilation of quantitative research results. From a phenomenological perspective, however, there is a problem with only using quantitative methods to research an area like the experience of parents of dependent handicapped children. Although quantitative research has revealed a great deal about the factors influencing the parents of handicapped children, it is questionable if the

accumulated information from this research actually improves our understanding of the phenomenon as it is experienced in the lives of the individual people. The reason for this is that the factors influencing or contributing to a phenomenon are very different from the actual lived experience. Moreover, even if there was a direct relationship between causal or correlational factors and lived experience, the whole lived experience is not the same as the sum of its contributing parts. The emotions, attitudes, and experience of these parents have a unity that is part of each individual, and this cannot be wholly explained or understood by analyzing and compiling the degrees of influence of individual contributing factors.

The Stage Theories

The second category of research predominant in the literature include the studies that relate to the proposed existence of a sequence of stages which parents go through in their adjustment to having the mentally handicapped child in their family. In a review of the literature on stage theories, Blacher (1984) listed over 30 different research studies, some dating back to the 1950's (e.g., Blodgett 1957; Boyd, 1951). A most significant development in stage theory research occurred when Hubert (1979) adapted Kubler-Ross' (1969) stages on death and dying in order

to attempt an understanding of the adjustment of the parents of handicapped children, and this model appeared to find support in subsequent research (Irwin, Kennell, & Klaus, 1982). A major component of the stage theory stemming from Kubler-Ross' work is that the parent must work through the stages of a grieving process related to the loss of the normal child he or she might have had.

Quite recently, the application of stage theory to the understanding of parents of the mentally handicapped has come under increased criticism. For example, Blacher (1984) concluded that, despite the popularity of the "stage concept", evidence of stages is limited almost entirely to clinical observations that are not substantiated by quantitatively reliable data. Allen and Affleck (1984) supported Blacher's position and added that a number of studies have indicated exceptional variability in parent reaction, as well as a paucity of support for stage-like reactions to any life crises (Kimball, 1969; McDaniel & Sexton, 1970; Silver & Woortman, 1980).

Not only have the clinical observation studies supporting stage concepts lacked quantitatively reliable data, they also have not used phenomenological procedures, which might have provided a good alternative considering that stage theory has a

life-descriptive component, compatible with phenomenology. No stage theory studies attempting phenomenological procedures such as bracketing presuppositions (Becker, 1986) or entering the "life-world" (Giorgi, 1970) of the subject seem to be available. The main reason why a phenomenological approach may have been preferable to clinical observations in the development and advancement of stage theory research is that the clinical observation stage theory research deals with parents in the context of the stage model, instead of allowing the model to emerge from the raw data. On the other hand, in phenomenological research, any life descriptive model or descriptive theme stems directly from the actual life-descriptive expression of the persons experiencing it. As a result, it has a basis in the actual lived experience of the people involved, whereas most stage theory research begins with the stage model and then attempts to examine how the model fits the parents in the research. Moreover, the original stage model (e.g., Kubler-Ross, 1969), was based not on lived exerience but on the second-hand and non-systematic observations of clinicians. It will be interesting to see if a progression through a number of adaptive stages of adjustment emerges as a main theme in this thesis as probably would be predicted by stage theorists.

Unless stage theory models have a real basis in most parent experience, their adoption as a reference by professionals dealing with the parents of the mentally handicapped could be causing problems. As suggested by Allen and Affleck (1984), there is a danger that stage models may create the risk of professionals pushing parents in directions dictated by the model, as opposed to working from adaptations exhibited by each parent. Indeed, it could generally be suggested that when professionals hold unrealistic or stereotypic expectations of parents, then communication can break down because professionals may not be able to recognize individual and real needs the parents are expressing.

Qualitative Studies

Two types of qualitative studies related to the parents of mentally handicapped children are of interest here. First, there are the accounts written by parents of mentally handicapped children about their own experience. These have taken the form of books written by the parents (e.g., Schaefer, 1978), or edited compilations of accounts by parents about their experience and feelings (e.g., Pivato, 1984; Turnbull & Turnbull, 1978a). Accounts like these do not suffer some of the disadvantages of the quantitative or stage model studies in that they represent the whole

experience, not its causal parts, and they are in the words of the parents involved, instead of being once removed and interpreted through statistical procedures or expert psychological observations. A problem with self-descriptive accounts, however, is that they do not generally make an effort to come to conclusions about the nature of their own content as a whole, and therefore one must rely on one's own surface impressions of the material.

When one reads the firsthand accounts, it becomes apparent that although they differ a great deal from one another, the overall content appears to be vastly different than many of the findings of the researchers studying the parents of mentally handicapped children. For one thing, both quantitative research and stage theory seem to concentrate on the negative aspects of having a special needs child in the family. For example, Wilken (1979) has related how references to the psychologically damaging effects of the mentally handicapped person on other family members is very predominant in the literature. Scales measuring degrees of problems or stress are frequently apparent (Gallagher, et al., 1983), and it has been mentioned that most stage theories are based on the parent adaptation to grief and sorrow (e.g., Wikler, Wasow, & Hatfield, 1971). Such negative aspects do appear in

some of the self-reports by parents compiled by Pivato (1984), and Turnbull and Turnbull (1978a), however, at least as much attention is devoted to positive aspects such as the joy and purpose brought to the parents' lives. This is something hardly dealt with at all in other literature authored by professionals about the parents of the mentally handicapped.

There is a second major difference between the literature written by parents as opposed to professionals. While most literature written about the parents of the mentally handicapped deals with psychological processes such as grief, sorrow, or adjustment, the literature written by these parents tends to deal with concrete issues such as time management, solving medical problems, or obtaining proper assistance from professionals and social agencies (e.g., Pivato, 1984; Turnbull & Turnbull, 1978a).

Apart from parent self-accounts, the other type of qualitative study relevant here are other phenomenological studies about the parents of mentally handicapped children. Wilgosh (1985) was the only study uncovered that used a phenomenological approach to reveal the experience of the parents of mentally handicapped children, in particular, parents of trainable mentally handicapped children. A possible

limitation of this study was that it dealt with the parents' attitudes towards life skills development, and thus it is difficult to judge the overall significance of life skills issues, compared to other feelings and concerns these parents may have had in the total picture of their experience with their mentally handicapped child. Nevertheless, this study did reveal a number of important themes suggesting considerable parent concern about their mentally handicapped child's skill development and the degree of feedback they received from psychologists and educators. The parent concerns expressed were very concrete and reminiscent of those in the self-reports written by parents themselves. The themes, however, were mostly of a negative nature. It is uncertain if this is a departure from the parent-written literature or something only relative to the life skill development issue examined by Wilgosh.

Conclusions of the Literature Review

It appears that past research related to parenting the mentally handicapped child mainly provides a choice between quantitative approaches, which may not reveal the phenomenon, and stage models, which do attempt an experiential description, but which can be significantly criticized from both a quantitative and a phenomenological perspective. Moreover, except for one

phenomenological study involving the parents of trainable mentally handicapped children, most descriptive accounts using direct expression from the parents lack a system for comparing and priorizing the importance of the content. Clearly this suggests the need for fresh conceptual approaches for examining what parenting dependent handicapped children is like. It is hoped that the phenomenological approach used here will represent such a fresh approach by accenting the benefits of examining data about the whole phenomenon from the direct experience of the source of the phenomenon (the parents), while still retaining some of the "validity" so commonly stressed in quantitative research.

Chapter III

Methodology

The content of this chapter deals with the methodological approach which includes the basic components of phenomenological research paradigm as well as the techniques and procedures specific to the thesis. As will be discussed in this chapter, there is not a great deal of consistency in the various procedures and techniques used by phenomenological researchers, thus one must choose which procedures and techniques are most suitable for one's use dependent on the nature of the research project. Because the author of this thesis is not an experienced phenomenologist, however, there was an effort to use intact procedures and techniques suggested by experienced phenomenological researchers. For example, the guidelines advocated by Becker (1986) were followed with regard to phenomenological techniques such as interviewing and bracketing, and the data analysis used in the thesis is faithful to the six steps for analyzing phenomenological data as established by Colaizzi (1978). An exception to this use of established procedures and techniques occurred with the actual method of interviewing the participants or co-researchers used during the interviews for the thesis. Because of a clear lack of direction provided

by other authors, an interview technique was devised by the author of the thesis, as illustrated on page 55.

Initially, some important distinctions related to methodology, and the nature of phenomenological research itself needed to be clarified. First of all, it should be noted that phenomenological research very significantly deviates from the quantitative research which has traditionally dominated most psychological investigation. These two types of research differ not only in terms of method, but in terms of their core underlying paradigms, or sets of philosophical assumptions. It is necessary to deal with these underlying distinctions, otherwise phenomenological research may appear to be to invalid to those with a quantitative/statistical frame of reference. As a result, the assumptions of phenomenology and the rationale for its use have been dealt with in this chapter. Secondly, although phenomenological research has some traits in common with qualitative research as a whole, there are also essential ways in which phenomenological research is totally unique. A section on the specific characteristics of the practice of phenomenological research has been included to point out such uniqueness.

Assumptions of Phenomenological Research

There are several basic assumptions about human existence that compel phenomenologists to view human experience as the essential component of psychological inquiry. For instance, they believe that human consciousness is primarily instrumental in shaping the individual's interaction with the world (Valle & King, 1978). Behaviour is seen as a function of perception and personal meaning, rather than as a direct and predictable response to environmental stimuli (Combs, Richards, & Richard's, 1976). Operating from these assumptions, human behaviour ~~can~~ only be understood by knowing how different phenomena are perceived and interpreted by the individual or group of individuals, i.e., what the meaning is for him, her, or them. It is the interrelationship between perception, interpretation, and behaviour, rather than behaviour and environment, that is assumed to be significant. Consequently, in its attempt to understand the essence of human nature in all its complexity, phenomenology has emphasized the importance of exploring human experience and the conscious meanings attributed to it (Giorgi, 1971b). As a result, the methodology of phenomenology becomes largely descriptive. Obviously, quantitative methods are inappropriate since "subjective" consciousness is not observable or

quantifiable; nor is it reducible to isolated variables.

The phenomenologist's ulimate goal in exploring the diversity of meanings for individuals is to uncover their underlying structure (Giorgi, 1971b; Valle & King, 1978). The structure of a phenomenon has been defined as "...the commonality running through the many diverse appearances of the phenomenon" (Valle & King, 1978, p. 16). According to phenomenologists, the only way of apprehending this structure, and thereby gaining a basic understanding of the phenomenon under study, is through the exploration of conscious meaning (Valle & King, 1978). In the thesis, the structure is represented by the overall themes which are revealed through the exploration of the descriptions (meanings) from each participant or co-researcher.

Rationale for the Use of Phenomenology

Phenomenology is actually a paradigm of scientific inquiry as opposed to a method. A paradigm is a methodological model which is defined by an implicit or explicit set of beliefs or assumptions, and delineates both the questions which are posed by researchers and the ways in which they are investigated (Giorgi, 1970). Thus, phenomenology represents an alternative, not only to quantitative methods, but to the entire set of philosophical/methodological beliefs which underlie

quantitative methods. Phenomenologists refer to the beliefs underlying quantitative research as the "natural science paradigm", because it was first used for investigation in the natural and physical world and only later applied to human behaviour (Giorgi, 1970). The natural science paradigm and its quantitative methods have provided an excellent means of generating data with regard to the measurement of the influence of variables on one another. The experimental branch of the natural science paradigm has had particular success obtaining valid and reliable results about cause and effect relationships by treating psychology as human behaviour that is mechanical, repetitive, predictable, determined by the environment; and reducible to simple operational variables which can be manipulated, controlled and studied independently of one another (Valle & King, 1978). Contained in the natural science paradigm, however, is a philosophical viewpoint, stemming originally from the works of Rene Descarte, that divides the human condition into the "objective" observation of human behaviour and the "subjective" nature of human experience (Giorgi, 1970). Objectivity has become the goal of the natural science paradigm, and this can only be obtained by observing and measuring events according to strict rules of evidence using the senses. Human behaviour becomes the subject

matter of a field like pyschology since it is the only part of human nature that is observable and measurable using our senses. Because of this need for "objectivity", all that which is "subjective" (for example, human consciousness and human experience) is considered to be outside the limits of scientific investigation. In other words, to be objective is not to be burdened by the complications of the various ways people might experience a phenomenon and thus objectivity can reside where human experience is not (Colaizzi, 1978). Phenomenologists generally reject the natural science, "Cartesian split" philosophy dividing the subjective from the objective, and suggest instead a total alternative in the form of a phenomenological paradigm (Giorgi, 1970).

There has been a tremendous amount written about the philosophical/methodological basis of the phenomenological paradigm (e.g., Colaizzi, 1978; Giorgi, 1970, 1971a, 1971b, 1975a, 1975b, 1985; Polkinghorne, 1981; Salner, 1986; Stigliano, 1986; Taylor, 1971; Valle & King, 1978; Wertz, 1984). From this literature, it may be possible to propose three central concepts that suggest why the phenomenological approach may be a more appropriate paradigm than the natural science paradigm for advancing knowledge in

some areas such as understanding the situation of the parents of mentally handicapped children.

First of all, Giorgi (1970) has criticized the natural science paradigm for allowing its commitment to a predefined methodology to determine both the content and goals of psychology. He argues that although such assumptions implicit in this approach are applicable to the world of physics, they are not appropriate for the study of human beings. He feels that human thoughts and interpretations of the world are paramount to human behaviour and a more appropriate focus of scientific investigation.

Secondly, Giorgi (1970) and Valle & King (1978) contrast the natural science paradigm, which attempts to establish truth through building a pyramid of isolated cause and effect relationships, and the phenomenological paradigm, which views existence in terms of the existential-phenomenological notion of a wholistic "life-world". The concept of the "life-world" is complex, but it is essentially a pre-reflective entity which suggests that human experience is so interwoven with the world in which it takes place that it must be viewed as a whole, single unit or a "life-world". To separate human existence from the world in which it takes place and then explain the relationship between the two, in terms of cause and

effect, is thus inappropriate. Because life and world are indivisible, the summing of the established cause and effect relationships between them may not bring one closer to an understanding of the total phenomena. The whole is not the sum of the causal parts. As an alternative, phenomenology suggests we set a goal of understanding the life-world as an entity itself, which means one would want an accurate description as if through the eyes of the people or person living it.

Thirdly, Taylor (1971) and Salner (1986) have criticized the natural science paradigm and suggested phenomenology as an alternative because only the latter allows for an explanation that takes into account what these authors call "intersubjective meanings". Intersubjective meanings are described as the facts of human experience that are socially constructed. "The practices that comprise society or a culture (e.g., religious ritual, art, laws, and etiquette) are not given to nature as 'brute facts' that are isolable or measurable" (Salner, p. 108). Nor are they just subjective meanings, the property of one or some individuals, "but rather such intersubjective meanings are constitutive of the social matrix in which individuals find themselves and act." (Taylor, p. 119) In the case of this thesis, there will be a search for the essential structure or intersubjective meaning that

is the experience of the parents of dependent handicapped children. Moreover, it will be noted that such intersubjective meaning is also interconnected with the other intersubjective meanings around the parents: for example, the current beliefs, practices, and attitudes towards such things as parenting and the treatment of mentally handicapped children.

The Practice of Phenomenological Research

As indicated in the introduction to this chapter, the goal of this short section will be to briefly delineate the essentials of the practice of phenomenological research which make it distinct from other qualitative methodologies. Most of the information in this section is derived from Polkinghorne (1981a) who has provided the following description of phenomonological research practice:

> Phenomenological research seeks to develop presuppositionless, structural descriptions of what is given in experience. It uses specific methods designed to direct attention to what is given in human experience, to free the researcher from prejudgments about the data, and to bring to view the structural components through which experience is formed (p.4).

Polkinghorne initially listed a variety of the other qualitative methodologies and suggested that they

are related to phenomenology to various degrees; however, he has gone on to point out that there are three distinct components which, in combination, are completely unique to phenomenological research; " what is given in experience, presuppositionlessness, and structural descriptions" (p.4).

Attention to "what is given in experience" implies that the researcher is not interested in cause and effect relationships or whether something exists outside one's experience of it. The researcher wants to enter the life-world of the co-researcher by emphasizing only what is "given in the experience" of the co-researcher. Thus one needs a careful description of these "givens" from more than one perspective. "Just as physical objects look different depending on the angle of observation, so too the way one looks at human experience needs to be comprehended from a variety of perspectives before it comes into focus as a whole." (Polkinghorne, p.5)

Presuppositionlessness is the second essential component of phenomenological research. The ideal here is to allow the modes and objects of consciousness to be seen as they are in their original appearance. Thus, the researcher's personal presuppositions should colour the description as little as possible. Polkinghorne has suggested that we can never completely

rise above presuppositions rooted in our historical and cultural circumstances, however, a great deal of movement towards presuppositionlessness can be made if the researcher possesses an increased self-awareness and employs devices such as bracketing, to be described subsequently.

The third essential component of phenomenological research is the formation of structural descriptions which in the thesis will be identified as themes. Polkinghorne has provided an excellent explanation of structural descriptions as follows:

> The descriptions which are the final product of phenomenological research are not merely descriptions of surface aspects--that is, various appearances--of the "given." They are descriptions of the essential aspects of the "given"--that is, descriptions of what makes the "given" what it is. Since it is the structure which is to be described, various examples of the appearance of the "given" need to be compared in order to identify what is essential from what is particular to one of its manifestations. In order to develop structural descriptions, the researcher must collect a broad variation of examples of the appearance of the "given" and carefully uncover the structure which is essential in the examples.

> The researcher makes explicit the structure which is implicit in the various examples. Thus, the description of the structure must be allowed to emerge from an extensive comparison of the examples. A premature closing-off of the emergence, by imposing a presupposed understanding, invalidates the description. To prevent this possibility, examples created by imaginative variation are important. But most important is a test of the final structural description which can be made by returning to the examples to see if the structure is indeed present in each of them. (Polkinghorne, 1983, p.9-10)

Research Techniques

Phenomenological research currently has no universally accepted single methodological technique. As an illustration, Polkinghorne (1981b) has written a manuscript describing four examples of phenomenological research that use significantly different techniques. Van Manen (1984) also has written an essay on "doing" phenomenological research which is significantly different than Polkinghorne's examples and the techniques used in this thesis. Nevertheless, most phenomenological research does share the technique of using the researcher as a research instrument. Thus, the researcher's observations, inferences, and

especially his or her introspections are valued, in contrast to the natural science paradigm, where a distance between the researcher and the subjects is maintained in the interest of objectivity. Moreover, because meanings are more often implicit than explicit, the analysis of data obtained usually involves a process of thematicizing the descriptive data, wherein the researcher is further required to employ his or her intuitions and observations, as well as interpretive and introspective skills (Giorgi, 1971a). The two main research techniques employed in this thesis follow the above phenomenological dictums and are well accepted (Becker, 1986). They are interviewing and bracketing.

Interviewing.

When obtaining the raw data from the co-reseachers (in this case, are the parents interviewed), the goal is to enter the life-world of the co-researcher as much as possible so that a realistic understanding of what the experience has been like for the co-researcher is obtained (Wertz, 1984). The interview is considered an excellent technique for obtaining such a goal because it provides the human context that motivates the co-researcher to take up the difficult task of articulating complex lived experience. As noted by Becker (1986), the themes or structures the researcher wants to identify are deeply embedded in the relational

and dynamic world and are often difficult for the co-researcher to speak about, however, these themes or structures become clearly identifiable when the co-researcher speaks about his or her everyday experiences during the interview.

A danger of phenomenological interviewing is that the interviewer may end up unintentionally focusing or directing the co-researchers descriptions through the use of structured questioning. Becker (1986) has suggested that most human science interviewers avoid leading the co-researchers by beginning with a broad unstructured opening question and by generally using open-ended questions as much as possible thereafter. Becker, however, goes on to suggest that there is little consistency among interviewer techniques beyond this.

In the interviews conducted for this research, the following broad opening request was used with each of the co-researchers: "I would like you to start at the beginning and describe what parenting of a dependent handicapped child (or the child's name) has been like for you." As the discussion progressed, the following interview techniques, designed by the author of this thesis, were used to facilitate a more explicit meaning revelation and keep the description grounded in actual lived experience:

a) When the meaning seemed vague the researcher would ask for clarification or more specific experiential examples.

b) When the meaning seemed complex or difficult to understand, the researcher would attempt to paraphrase the main point and then ask if he was on target or not.

c) When the co-researchers began to intellectualize in ways that seemed less related to the topic, the researcher would ask about the relationship to their own experience with their child.

For some co-researchers the above input was sufficient. It was found, however, during seven out of ten interviews, that more specific questioning input from the researcher was required in order to maintain a good flow of self-expression. When this occurred, the interviewer asked the co-researchers to expand on important points they had expressed earlier or asked them whether themes indicated in earlier parent interviews were significant for them. The latter technique is advocated by Kvale (1983) and Wertz (1984), who have suggested developing a pool of questions based on previous interview themes. Overall, it was hoped that only questioning about significant data obtained from an interview source would tend to

limit the possibility of too much interjection stemming from the researcher's preconceptions.

Bracketing.

Bracketing is basically a process in which the researcher clarifies his own presuppositions about a topic and then separates and contrasts these with respect to the co-researcher's descriptions (Becker, 1986). Becker has suggested that the bracketing process greatly enhances the validity of phenomenological research. Validity, as Salner (1986) has pointed out, is a term bounded by the context of the natural science paradigm and its emphasis on objectivity. Salner suggested that phenomenological research would be better served to talk in terms of "defensible knowledge claims" (p. 128) and she made a number of important distinctions between the two terms (p. 111-128). Nevertheless, the phenomenological goal of describing the life-world of co-researchers involves the use of researcher interpretations to enrich and delineate the co-researcher description, as opposed to having the researcher's presuppositions impinge on the structure of the interpretation. Bracketing is a technique for preventing the latter and facilitating the former.

The first step in bracketing, according to Becker (1986), and the process used here, is for the

researcher to spend time becoming aware of his or her preconceptions. Personal life events, especially aspects of the phenomenon that are highlighted in his or her experience need to be considered. Becker suggests that, "...writing down these experiences, or talking to a friend about them and audio-recording it, may help the researcher to bring his or her implicit knowledge of the phenomenon to an explicit level of awareness" (p. 114).

The following personal account was composed by this author in the autumn of 1986, prior to most of the interviewing for this project, and it represents an attempt at the identification of preconceptions for the purpose of bracketing here. The personal nature of the account necessitates a switch to the first person singular for the narrative:

> Probably my experience as a parent has had a great deal to do with my preconceptions of what it would be like to be the parent of a dependent handicapped child. In particular, I recall the period immediately after the birth of our son as an extremely joyful and intense experience. On the second day of my son's life, however, a pediatrician informed us that my son might have a serious, and possibly life-threatening, bowel obstruction. Fortunately, this turned out to be a

false alarm, but the feeling of crashing down into a state of helpless dread that occurred for me at that time is not one I will easily forget. A non-parent might find this to be similar to, but much worse than, feeling well-prepared walking into a final exam and suddenly not knowing any of the answers. For me, this experience represents a partial insight into what it would be like to be told, "I'm sorry, but our tests suggest that your child is severely mentally handicapped." I feel that this could not help but result in an intense sense of sorrow and grief trauma that would alter itself only slowly over time. It is difficult for me to imagine how any long term satisfaction would develop from constantly looking at your mentally handicapped child and imagining the "normal" one who is never going to emerge.

A second set of experiences that has likely influenced my preconceptions are those related to my work as a special education consultant for a school division in a small Alberta city. In this position, I have frequently come into contact with the parents of handicapped children, usually during a parent conference. These meetings serve a useful purpose, but I often feel that parents feel threatened in spite of good efforts to prevent this. Sometimes these meetings even have

> a confrontational nature as parents fight for more services for their child. Generally this experience has led me to the preconception that the parents often develop negative, or at least cynical, attitudes towards professionals over a period of time. I have felt as though there is a wall separating these parents and professionals and somehow I must jump to the other side and see what is really going on.

Once initial preconceptions are bracketed as they have been above, the researcher continues to monitor and often record a changing awareness of his/her biases and preconceptions as the research progresses (Becker, 1986). As a result, the actual co-researcher description is frequently contrasted against the bracketed presupposition, and thus, the presuppositions are gradually whittled away. This contrasting process and whittling away of presuppositions is combined with an intuiting process (Aanstoos, 1985) and gradually this leads to the reduction (Giorgi, 1985) of the raw data. In other words, the researcher uses bracketing and intuiting (illustrated by Colaizzi's six steps, to follow) in order to gradually strip away the non-essential part of the raw descriptive data and reveal the essential meaning that best represents the life-world of the co-researchers.

Research Procedure

In this section the step-by-step procedures used by the researcher towards obtaining conclusions in this study will be discussed. The main steps were the selection of co-researchers, the interview procedure, and the analysis of the data.

The co-researchers in the thesis.

Because of the personal nature of the thesis, the co-researchers were volunteers. It was felt that self-selected participants would be more willing to share their personal thoughts and feelings related to their experience. The initial contact in Edmonton was made through a professor at the University of Alberta. Subsequent Edmonton co-researchers were obtained through a contact who knew a large number of the parents of dependent handicapped children because of a long term involvement in an Edmonton parent association. This individual was able to provide the researcher with a list of parents who had expressed an interest in the study as a result of an advertisement at a parent association meeting. The Fort McMurray parents were volunteers originally contacted through the school program attended by the children. Parents who had previously met with the researcher were not selected for this study since it was felt that this might alter the basis of the interview.

There were some general requirements for participation in the project. The first requirement was that the mentally handicapped child be enrolled in a recognized school program for the dependent handicapped. It was assumed that some form of assessment is done in order for students to be selected into such programs, and, thus, the parents of higher functioning children would be effectively screened out of the study. This requirement also effectively screened out the parents of very young handicapped children since they would not yet be in a school program. However, this early period is frequently a time of uncertain diagnosis, so there would be no certainty that the child was really dependent handicapped. The second requirement for participation was that the dependent handicapped child be living in the parents' home. It was felt that the experience of parents whose child was institutionalized, or living primarily in a group home, would be different from the experience of a parents who needed to continually care for their child in their home.

The researcher also attempted to have some diversity among the co-researchers in terms of the circumstance of the co-researchers, as well as the age, sex, and specific handicapping conditions exhibited by the dependent handicapped child. Several experienced

phenomenologists (e.g., Alapack, 1973; Aanstoos, 1983; Wertz, 1984) have found that having extreme contrasts among the co-researchers often helps to illuminate the structure and constituents of the phenomenon. Of course, in this study, the small size of the group, and the availability of people, limited the diversity of selection. However, it was felt that a fairly reasonable cross section of the parents of the dependent handicapped, within broad limits, did participate.

The co-researchers consisted of 18 individuals. This group of 18 consisted of: one single mother, one married mother interviewed by herself because she indicated that her husband's job demanded that he be out of town most of the time, one single father and a partner who had shared the care-giving demands with him for a period of time, and 7 pairs of parents (14 individuals) with both the mother and father interviewed together. The parent(s) of each dependent handicapped child were interviewed only once, and thus, there were 10 interviews which took place. The men interviewed included; highly trained professionals, business employees or managers, and tradesmen or other somewhat specialized workers. Only two of the women interviewed were employed full-time outside the home (one very recently). The rest were either not employed

or held part-time jobs. A majority of the women had received some form of job or professional training, but only one was actively pursuing a career in the area in which she had trained. Fourteen of the co-researchers are Edmonton residents and four live in Fort McMurray, Alberta.

The dependent handicapped children range in age from 6 to 17, and consist of seven males and three females. They have a variety of physical handicapping conditions in addition to mental retardation. In the group, six currently require at least partial wheelchair assistance and four do not.

Interview procedure.

The co-researchers were initially contacted by telephone to explain the nature of the study and to ensure the desired co-operation. All of the interviews took place in the home of the co-researchers. During the initial stages of each interview, rapport was established and the confidentiality of information assured. Consent forms confirming confidentiality were signed by the co-researchers and the researcher. Subsequently, further information about the interview technique was discussed. The audio-recording began with the initial opening request, as outlined earlier, and proceeded in a relaxed manner. Each recorded interview lasted from 1-1/2 to 2 hours. All

co-researchers expressed an interest in the study results and it was agreed that a summary of the results would be sent to them.

The initial parent interview took place during October, 1986, and the resulting transcript was incorporated into a phenomenological pilot study relating to the experience of these particular parents. This pilot study was presented as a term paper for a graduate course in phenomenological research, being taken by the researcher at the time. Subsequent interviews were held between January and April, 1987, although the parents were not recontacted until August, 1987 to further validate the themes as suggested in step six of Colaizzi's (1978) data analysis procedure.

Data analysis.

First of all, the tape recorded descriptions were transcribed and the transcriptions were used as a protocol. The resulting information was explicated and organized according to a process outlined by Colaizzi (1978). A complete explanation of Colaizzi's data analysis steps has been included in this thesis document (see Appendix II); at this point, however, the main aspects of Colaizzi's data analysis steps can be outlined as follows:

1. Read the descriptions to acquire a feel for them.

2. Extract phrases and sentences that directly pertain to the investigated phenomenon. This is called Extracting Significant Statements.

3. Formulate meanings for each significant statement and use creative insight to leap from what the subjects say to what they mean.

4. Repeat the above for all protocols and organize the aggregate formulated meanings into Clusters of Themes.

(a) Refer back to the original protocols in order to validate them.

(b) The discrepancies among and/or between themes may be noted.

5. Formulate an Exhaustive Description of the investigated phenomenon in as unequivocal a statement as possible.

6. Return to the co-researchers and ask them, "What aspects of your experience have I altered or omitted?" (p. 54)

It should be noted that Colaizzi's (1978) system is not the only accepted process for organizing descriptive data. For example, Giorgi (1985, p. 10) provides an alternative set of steps which contain some significant discrepancies from Colaizzi. Colaizzi's approach was chosen for this thesis because it seemed a bit more straightforward than others and because it

appeared to lend itself well to the type of data obtained here. A possible problem with Colaizzi's steps is that he does not include the bracketing process, described earlier in the six steps. It should therefore be understood that the bracketing of presuppositions, as prescribed by Becker (1986), will be a part of the meaning formulation in steps 2 through 5. For the purpose of clarity, the reporting of the contrast between the exhaustive description and the bracketed presuppositions will take place in the discussion and conclusions of the thesis.

Chapter IV

Results of The Study - Themes

In this chapter the themes, which have emerged from the co-researcher's self expression, will be presented and integrated. The term "themes" is used here instead of "structural descriptions" (Polkinghorne, 1981a) because the former appeared much more self-explanatory and less technical. For each theme, a discussion about the central nature of the theme will be combined with a documentation of the variations within the theme as exhibited in the co-researchers' individual self-expression. In the theme variations there was a preference given to quotations which had a concreteness and particularity that is in keeping with phenomenology (Giorgi, 1971a). A section explaining the interpretation of the themes and interrelationships between them, is also included.

In terms of the six steps for data analysis proposed by Colaizzi (1978) and used in the thesis, the theme clusters (step 4) are identified as main headings in the chapter. The exhaustive description (step 5) is presented with regard to individual themes initially, and subsequently in a integrated fashion. It should be realized that step 6 (returning to the co-researchers for validation) also occurred, although the contact was made by telephone as opposed to a personal interview. There are two specific reasons why a documentation of

Colaizzi's steps 2 and 3 are not included. First of all, the sheer length of extracted significant statements (step 2) and their associated formulated meanings (step 3) precludes their inclusion in this document. Secondly, the co-researchers were assured of confidentiality prior to the interview and thus it was necessary to edit, and select from, their statements to ensure this. As a result a straight documentation of significant statements (step 2 and 3) could not be included.

The themes that are presented here are split into major themes and minor themes. Three themes have been considered major and two are minor. This division is more a product of the nature of the results obtained than a compliance with any phenomenological method. It happened that 3 themes are quite dominant, while 2 others presented themselves to a lesser extent, therefore, this distinction was incorporated into the results. Generally, the major themes were also present as major themes in the majority of the individual parent cases and present at least as a minor theme in all of the cases. The minor themes, on the other hand, were only present as a major or minor theme for the majority of separate sets of parents.

In order to protect the confidentiality of the co-researchers and their children, all names included

here are fictional. In addition, specific details in the quotations from the co-researchers have been omitted if it was felt the details might tend to provide clues about the identity of the co-researcher.

Theme 1 - Predominant Influence on "Life-World" Of The Mother (Major)

At first glance the suggestion that the dependent handicapped child has a tremendous influence on his or her mother may not seem to be a particularly distinctive theme. After all, surely all children, handicapped or otherwise, have a very strong influence on their mothers. What is being suggested here, however, is that the influence of the dependent handicapped child on his/her mother is exceptionally predominant and perhaps the single most determining and long term influence on the "life-world" (Giorgi, 1970) of the mother. There appears to be a basic uniqueness about being the mother of a dependent handicapped child both in terms of the extent of the child's impact on the mother and in terms of a fundamental difference in the nature of the influence. As a "normal" child or even a moderately handicapped child develops within a family, the focuses of the mother's life can be in many areas, such as a career, other children, the marriage, community involvement, etc. However, in the case of the dependent handicapped child all of the mothers

interviewed portrayed their lives as largely centered around, or directed by, the child. This was the case regardless of the age of the child. One should keep in mind that the "mental age" (Terman & Merrill, 1973) of these children is often under the two year level. This, in addition to the accompanying physical incapacitation means that the mother or care-giver spends vast amounts of time serving basic needs.

It will be shown that there has been a great deal of individual variation in the way that mothers cope with the long term and predominant impact of the child. None of the mothers, however, failed to suggest the overwhelming and determing nature of this impact. As Mrs. A. stated, "I almost feel like I have developed into a totally different kind of person in the years since we had Andrew...I know my life would have taken a completely different course if we would not have had him".

Variations of Theme 1

The purpose of this section is to highlight the actual statements of the co-researchers that contribute to the make-up of theme one. There are several specific variations in the way groups of co-researchers have described their life experience as related to the theme and it is hoped that an illustration of these

will contribute to a documentation of both the richness and the unity of the theme.

1a. Physical and mental strain.

Because the sheer time and labour involved in looking after a dependent handicapped child is so extensive, it is perhaps not surprising that many mothers spoke a great deal about the day-to-day physical and mental strain that this entails.

Some of the more severe examples of this were given by Mrs. B. and Mrs. C. Mrs. B. described a period of several years when their son (now an adolescent) continually failed to sleep through the night. Thus she and her husband often had to get up and comfort her son. Mrs. B. describes herself during those years as: "...being in a continuous state of absolute exhaustion". She reveals that it is only since her son started to sleep through the night in the last couple of years that: "I realize what it is like to walk around feeling rested and clear-headed instead of like a zombie". In a similar revelation Mrs. C. remembers that her son engaged in the self-stimulatory behavior of frequent high-pitched screaming during a period of three to four years, in his earlier life. She stated:

> The screaming nearly drove me crazy...I always had a bad headache at the end of the day and was

> really addicted to 'Tylenol'. Later I sort of got used to it and it didn't bother me so much. It was around that time that I found out the screaming had caused a hearing loss so I guess it didn't bother me as much because I couldn't hear it as well (laughs at this point).

Another physical strain relates to the necessity of lifting. It is a simple fact that most multiply handicapped children need to be lifted from place to place several times a day. This, of course, becomes more difficult as the child becomes heavier. Several of the mothers interviewed stressed this difficulty and several also stated they had back problems related to the lifting. Mrs. D. described how:

> Eventually my back was so bad that we had to hire a helper just to help me with lifting Denise. The problem was that the people we hired didn't like the lifting any more than I do. (At this point she turns to her husband.) How many helpers do you figure we've had, dear?

Like Mrs. D., almost all of the co-researchers had long comments to make about the sheer volume of physical and repetitive work involved in looking after their child. Mrs. E., for example, described the situation in a slightly different way:

> You know I'm not the type to whine and complain like some of the parents at those meetings, but if you really want to know what it's like around here (meaning on a day-to-day basis in her house)--well it's one hell of a lot of work...we've got three kinds of programs running here and one heavy little boy (meaning her dependent handicapped son). You'd have to pay me a pretty good wage to do this stuff for somebody else.

1b. Life restrictions.

In addition to physical and mental strain the parents also put an emphasis on how the care giving demands had a long term restrictive influence on their lives. With regard to the life-restrictive aspect, it is worth noting again that only one of the mothers interviewed held a full-time job and none of the women had pursued former career interests after the birth of their dependent handicapped child. Most of the mothers suggested that the demands of their child, in fact, had prevented a career or full-time employment outside the home. Mrs. F.'s situation was fairly typical as she described the following:

> I haven't been able to work since we left (named the town they lived in until shortly after Frederick's birth)...if we hadn't had Frederick I'm sure I would have pursued my career as a

> (named former career)...it really seems a shame that I've wasted all my education and never worked for very long at what I planned to do...lately I've been thinking about getting some kind of job, but he (Frederick) is really only out of the house (meaning at school) for about five hours a day and it would be a pretty funny job which fit exactly into that time.

Obviously the mothers who were contented as homemakers, or didn't have outside-of-home career or job aspirations, would have fewer concerns with regard to career restrictions and this was reflected in their discussions. However, these mothers had similar concerns with regard to restrictions the dependent handicapped child had placed on their life-development over a period of time.

An example of the above situation was Mrs. G. who has an adolescent multiple handicapped daughter in a wheelchair. She stated that:

> People who don't have a handicapped child don't know what being tied down is all about...because our daughter has such special needs it's impossible to get anyone to look after her so one of us (meaning herself or her husband) has to be with her all the time...we can't go out anywhere together unless we take her with us...you can't even leave to get some milk at the store without a

major production of getting her ready to go. So basically we each do our own thing and we have to plan whose turn it is to look after Gina ahead of time...it's been that way for years.

At this point Mr. G. adds:

We find that people who don't have handicapped children just don't understand our situation...you get social invitations you have to turn down because of Gina and the people get offended...we find now that our friends are mainly the parents of other handicapped children who understand where we are coming from.

This is a fairly typical description of the restrictive influence of the dependent handicapped child. Mrs. G., however, is fortunate because her husband shares the care-giving demands with her to a large extent. Slightly less than half the other mothers interviewed were either single parents or had husbands who did not significantly share in the care-giving tasks for various reasons. For these women the total weight of the care-giving demands fell on their shoulders. As a result they were restricted from furthering any life development that did not involve their dependent handicapped child. Mrs. L., a single mother with a younger dependent handicapped child described this situation as follows:

It's like having a baby who gets bigger but he never grows up. You just keep feeding him, lifting him, and those diapers they just go on and on--(sigh) don't get me wrong, I really love Hal but sometimes it just feels like I'm spending my whole life in this house looking after him, do you know what I mean?...lately I've been dropping him off at the group home just so I can do some stuff, shopping or whatever, on my own...but he acts real bad when he's there and they make me feel guilty when I pick him up...so I don't know if that's such a good idea. I thought it would be different when he started school, (he had just started in a full-time school program the previous September). I was taking this course in (names a job training related course) in the fall while he went to school but around the end of October there, Hal started having all kinds of seizures again and had to go into the hospital for a while...anyway I ended up dropping the course (long pause). I don't seem to have any time to get anything done for myself.

This is a more extreme example of the life-restrictive aspect of the overwhelming influence theme. Almost all of the mothers, however, referred to

ways in which the dependent handicapped child had restricted their life-development to some degree.

1c. Personal development.

In addition to restricting the life development of the mother of the dependent handicapped child, in many ways there often seems to have been created a growth in the personal development of the mother. In both respects the influence on the mother has been very predominant or overwhelming, as mentioned earlier. Interestingly many of the same mothers who spoke about the restrictive influence of the child on their lives also spoke in terms of the personal development created by their children. This may seem like a contradiction to some readers, however, the contradiction was not apparent in the minds of the co-researchers. This may be because the dependent handicapped child caused both life-restrictions and personal development in different aspects of the mothers' lives. Actually only seven out of ten of the mothers referred to this personal development. Of this group most spoke of personal development through the mother-child relationship or growth through the advocacy role they had adopted for their child. An example of personal growth or fulfillment in the context of the mother-child relationship has been provided by Mrs. I. "We spent a lot of time helping our older son too, but really it

seemed like he picked up so much so fast and almost on his own. (Here Mrs. I interrupts to say) "one minute he's sitting in his crib, next thing you know he's asking for the keys to the car." (both parents laugh at this and Mrs. I. continues):

> But with Ian everything he learned took such a long time and so much work from us that when he did finally get it we were absolutely elated. I can remember greeting (husband's name) at the door all excited with some big story about how Ian had done some simple thing like grasp his fork or something and then of course he'd never do it when (husband's name) was there.

An example of a parent achieving a high level of personal development through advocacy for her child was provided by Mrs. J. Mrs. J. describes the early years of her handicapped child's life as a time when "you are in that terrible helpless feeling place where you watch your child but you can't do anything for him and he doesn't respond to you". Her response to this situation was to "get her dander up" and take the necessary steps over a period of time to learn how to help her child and get the best from others helping him. By becoming an involved advocate for her child, Mrs. J. described not only how she was able to help her child but how her advocacy was part of a personal

development process that ended in a life-career commitment to the field of mental retardation. Although Mrs. J. was the most extreme example of the co-researchers experiencing personal development through advocacy for their child, a number of other mothers spoke of this. Another mother gave a detailed account of how she learned the "special tricks you need when trying to get what you want from all those learned ones and money holders that control the resources I need for my child". She feels that the necessity of advocating for her child has taught her a greater self-confidence and self-determination than she previously had. This was expressed by Mrs. E. as follows:

> When Eddy was really young I used to let every different expert we saw push me this way and that, I figured they knew best just because they had some degree on the wall...now I figure they better sit and listen to what I have to say cause I know my child and I've got a pretty good idea what's best for him. I don't go along with anything just because people say I should.

Theme II - Very Strong Feelings About the Type and Quality of Assistance Received From Social Agencies or Professionals (Major)

The parents of handicapped children, on the whole, have a much greater contact with various professionals and social agencies than do other parents (Gallagher et al., 1983). It seems probable that this contact is even more frequent among the parents of the dependent handicapped because the frequent multiple handicaps of this group necessitate an even greater degree of diverse professional attention. In most cases the dependent handicapped children of the co-researchers were currently under the care of two or three different professionals and all of the co-researchers made detailed references to an extensive history of involvement with professionals and social agencies over the years. The main point of this theme, however, does not involve the extent of the parent involvement with professionals or social agencies, but the very strong feelings the co-researchers have developed with respect to this involvement.

It is a characteristic of western society that a network of social help systems has been developed to assist parents when their children have medical or development difficulties. Moreover, parents have learned to expect, and put a high degree of faith in,

this assistance. The days of home treatments and remedies are long past. It is probably predictable, therefore, that all co-researchers interviewed here did approach a variety of professionals and social agencies early in their child's life with the expectation that they would receive appropriate and effective assistance for the difficulties their child was facing. In almost every case, however, the initial positive expectations gradually faded with continued interaction with professionals and were replaced by very strong reactions ranging from total frustration, to general distain, to strong but mixed negative or positive feelings depending on which professional or agency the co-researchers were referring to. At first the researcher felt that the co-researchers' emphasis on professional/parent interaction may have partially been a response to the co-researchers' perception of the researcher as one of the professional group. In subsequent interviews the researcher attempted to downplay his own background in the field, and also carefully omitted any reference to parent/professional relations in the questions asked. Nevertheless, the co-researchers' references to parent-professional relationships occurred as frequently in later interviews as earlier ones and gradually the researcher concluded that the phenomena represented a major

component of the "life-world" (Giorgi; 1970) of the co-researchers.

Variations of Theme II

The strong feelings that the co-researchers expressed about professionals and social agencies with which they had come into contact ranged from very negative to very positive. However, on the whole many more parents had mainly negative feelings about the professionals they had dealt with.

2a. Frustration over not obtaining a proper degree of assistance for their child.

Examples of the frustration parents have experienced when trying to solicit proper assistance for their child are abundant in their verbal expression. Indeed examples of negative and frustrating parent experience are available with regard to many types of professionals, including psychologists, teachers, hospital staff, speech therapists, physiotherapists, doctors, medical specialists as well as local hospitals and social agencies. An example of a father's frustration with the variety of doctors his son had seen was expressed as follows by Mr. J.:

> John has been on so many types and dosages of seizure control drugs over years now that we have completely lost track of them all. The doctors

just don't seem to be able to prescribe the right thing for him, either he is completely drugged up or he is having seizures every three minutes. One guy tried so many different creative drug combinations that I finally just told him I wouldn't stand for my son being a guinea pig in his drug experiments anymore. I feel the doctors just don't know what they are doing with John. You could get extremely angry with the situation if you let yourself.

Similarly, Mrs. C. summed up her experiences with assessments done on her son at a local institution as follows:

Really I feel that all our trips to the (name of institution) were a complete waste of time. I remember one time they decided Craig was deaf...so we brought in a little rubber animal with a bell in it and showed them how he could track the sound. Then they said maybe he's not deaf...and another thing, they have no regard for the child's schedule whatsoever. They assess them at their convenience whether the child's tired or not, then they have the nerve to talk so confidently about their results. Really I feel the only thing the whole process did was add to the stress we already had at the time. I don't think anything ever came

out of it and there is no way I'd ever let the (name of institution) touch him again.

Among the most frequent contacts that the co-researchers have are with teachers in their children's school programs. They indicated some feelings of frustration with the teacher-parent relationship, although such feelings were not universally the case with every educator contact. In every single case it was the researcher's perception that there was more emotion (negative or positive) associated with the dependent handicapped child's school programming than would be the case with normal children. Perhaps this was because of the potential effect of skills learned at school on the day-to-day lives of both the parent and the child.

Mrs. B. suggested the following fairly typical feelings about her experience with educators concerning her son:

> Brian has a really nice girl who's been his teacher since September. She's got lots of enthusiasm and I kind of enjoy the little conferences we have...the problem is that she is always trying to continue his school programs at home, and now we sort of feel that the time we have with him at home should be different and more enjoyable than his school time. Besides most of

> the things they suggest now, we have tried before and it hasn't worked. He really hasn't changed that much in any real ways by being at school...mostly now we just agree with everything the teacher says and then go home to do exactly what we've always done.

At first glance the tone and content of the above quotation may appear to reflect an ambivalence about the child's educational program as opposed to strong feelings about it. However, it should be noted Mr. and Mrs. B.'s son was one of the more severely physically and mentally handicapped adolescents of the co-researchers' children, and thus over a period of time, they have experienced a variety of educational interventions which have not greatly increased his functional self-help skills in ways completely beneficial to his parents in their day-to-day activities with him. One is left with the impression that they have tried a number of interventions suggested by school programs over a period of time and generally have been frustrated and upset by the child's lack of progress and also by the lack of consistent long-term directions they have received. It appears these previous experiences and the strong feelings associated with them, and not an ambivalence about their child's education, have lead to some degree of

self-protective ambivalence with regard to the suggestions of their son's current teacher.

Another good example of parent frustration with education programs was given by Mrs. G. who is quoted as stating:

> At one time Gina was in a classroom with some other handicapped children, some of them were walking around totally out of control. One kid screamed all the time, another used to like to pull hair, especially Gina's. The teacher couldn't do anything with this class...we were really worried and Gina was going downhill. Finally after about three fights with the principal we got her out of there and into a different program. We've learned that you just can't count on 'them' to do the right thing for your child, often they make decisions convenient for their system but not necessarily good ones for the child. Gina is in a pretty good class now and the teacher seems okay, I guess, but we still keep a close eye on things to make sure it stays that way.

2b. Gratitude toward specific professionals who have helped them.

Although two of the co-researchers make no specific reference to the positive effects of

professionals or social agencies that they had encountered, the majority of co-researchers also had strong positive feelings about some specific professionals who had assisted them. The range of professionals to whom this applied was considerable although it tended to center around individuals who had a more frequent daily contact with the child. Mrs. D., for example, made the following comments about some of the teacher aides who had been involved with her daughter:

> Some of the teacher aides that Denise has had, have been very important in her life. She still goes around saying, 'Jenna, Jenna' (fictional name) all the time, even though we haven't heard from Jenna in two years since she moved to British Columbia.

The researcher confirmed that Jenna was a teacher aide Denise had for several years and then Mr. D. interjected, "You see, because Denise is so bound to that wheelchair, she doesn't have that many friends her own age so the teacher aides become like her friends and really can have a positive influence on her." Mrs. D. again added, "Yes, and both Jenna and the aide Denise now has, have taught Denise so many useful things...there is just so much she can do now that I never thought would be possible a few years ago."

Several other parents also expressed a considerable degree of gratitude toward specific professionals who had assisted them a great deal with their children. In almost all cases, however, the number of professionals who were of greatest assistance were outnumbered by those who were not, at least in the context of the descriptions given by the parents. The researcher also came to the conclusion that most co-researchers were in part very grateful to particular professionals they felt had helped them, simply because this contrasted so much with the majority of professionals who had not.

Theme III - Deep Concern About the Future of Their Dependent Handicapped Child (Major)

Because dependent handicapped individuals require long-term close supervision and self-care assistance from others, many co-researchers expressed considerable concern about what would happen to their child when they (the parents) could no longer act as primary care-givers. On the whole, the theme was quite major among all of the parents of adolescents and present at least as a minor theme among the parents of younger children. Most of the co-researchers revealed that they only gradually realized the extent of their child's difficulties and how slow the rate of progress was going to be. Thus initial hope of significant

progress or even recovery was replaced gradually by a realization that their child would remain very dependent on others into adulthood. With the later realization, a concern about how their child would be looked after in the future was only natural. The co-researchers also noted some other factors which were contributing to their apprehension about the future of their child. For one thing the interviews took place not long after the Alberta Government announced severe cutbacks in social services funding and many parents expressed fear that this would limit the future placement options for their child. In addition, previous frustrations that many parents had had with receiving proper support for their child, greatly contributed to a high degree of skepticism about the type and quality of placement assistance they might receive in the near future.

Variations of Theme III

There was a considerable amount of uniformity in the way the co-researchers talked about their concerns for a long term future of their child. Perhaps this was because each parent faces a similar set of options and decisions in the current social assistance network structure. Basically, there were two variations in the way parents discussed the future of their dependent handicapped child.

3a. Concern that child may not adapt to future placement other than the home.

Given the amount of time that mothers of dependent handicapped children spend with the child, it is understandable that a very close and special bond would be formed between mother and child. Also because the child does not achieve a significant degree of independence as he or she gets older, there may not be a loosening of these bonds as occur when "normal" children begin to seek an independent life for themselves. Thus several parents (mainly the mothers, it seemed) expressed some concern with regard to having other people look after their child. This was expressed succinctly by Mrs. I. in regard to her adolescent son:

> Even if we do find an opening somewhere soon that Ian can go to, it's going to be really hard for me to see him go to live there. There are just so many things he likes and dislikes, so many routines that he needs in order not to get upset. I don't know if someone could do that with him. It's not so bad when he goes to school because he knows he is going to see me at the end of the day but any time we've left him over at (names a group home which provides relief childcare for parents of handicapped children) for a few days, he's

always in just terrible shape when we pick him up. It takes me a whole week just to get him back on track. I know he's too dependent on me and I know we can't keep him with us much longer but I don't know what I can do about it.

For obvious reasons, the future of the dependent handicapped child was less of an immediate problem for the parents of younger children. They also, however, expressed concern about whether the child will be able to adapt once outside their care. Mr. J. indicated this concern from a slightly different perspective:

You know time is very important when you have a multiple dependent handicapped kid. Every day you waste by not teaching them is lost forever. We lost the first two years of John's life by not being able to help him and I'm just afraid that if we don't continue to press now, he's going to still be completely dependent as an adult and a complete burden to whoever is looking after him for the rest of his life. I just don't want it to end up being that way if we can help it.

3b. Concern over the adequacy of future services for their child.

This part of theme three is also closely connected to theme two in the sense that it relates to overall concern about the degree of assistance the

co-researchers have been able to obtain for their child. It was included here, however, because of particular relevance to the theme called "concern about the future". In the case of the parents of older children there was a great deal of concern expressed about what would be available for their child when adulthood was reached. Mrs. A., who, with her husband, had investigated placement options for their son notes:

> First of all it was quite difficult to actually track down all the placements that were available for someone like Andrew but once we got that sorted out, we quickly realized that we are looking at long waiting lists for every kind of placement in the city...there are 96 on a waiting list for only eight beds. It doesn't matter exactly how many are on the waiting list anyway because there isn't that much movement in those places so it looks like we're going to be waiting for quite a while...meanwhile Andrew sure isn't getting any lighter.

In addition to concern about future placements of their children, the co-researchers, in several cases, also expressed concern about the future contribution of educational programs. For example, Mr. F. indicated the following:

> The problem with the school program for the kids like Frederick right now is that it just stops at a certain point and I've never understood that. He has got all kinds of skills he needs, and after 18, I think he is going to need more of the same instead of something different. Also he really likes the routine of going to school and coming home everyday. I would hate to see that stop for him.

Theme 1V - Ongoing Stress and Anxiety (Minor)

Earlier it was suggested that indications of ongoing stress and anxiety in the parents of mentally handicapped children are quite predominant in the quantitative literature on this topic (Gallagher et al., 1983). Although the presence of this stress and anxiety did not come through as a consistent major theme in the thesis, it did so as a minor one. This type of theme is more difficult to identify because the parents tended to talk about the circumstance (e.g. care-giving demands, problems with professionals, etc.) creating stress in their lives, rather than the stress itself. Stress will be defined here as an excessive long-term emotional reaction related to tension and anxiety. This is not the same as the everyday living stress that everyone experiences. Just because the parents were describing very difficult situations they

had lived through, it was not assumed they experienced long-term stress unless they mentioned some kind of personal emotional reaction that might be indicative of stress. Nevertheless, in many of the protocols there were intermittent tell-tale statements throughout which suggest their personal reactions during these experiences were stress and anxiety. Thus it was not difficult to conclude that the presence of anxiety and stress in these parents should be considered an overall theme. However, it should be noted that although the stress theme appeared fairly major in five out of ten protocols and as a minor one in two more, there were three protocols in which no content appeared to suggest the presence of excess stress at all. These latter parents did face many of the same difficult situations as the others but there was nothing to suggest that their reactions were especially stressful. Since not all parents appeared to experience stress it is therefore being listed as a minor theme.

Variations of Theme IV

In all cases showing stress there appeared to be two main factors which mitigated the development of stress in the parents, and not at all coincidentally, both of these factors also strongly relate to other themes in this thesis. Stress appeared to be referred to in relationship with not being able to provide or

receive proper training or treatment for their dependent handicapped child, and when the overwhelming influence of care-giving demands became too much for the care-givers.

4a. Stress related to a lack of proper parent or professional assistance for the child.

A good example of this is provided by Mr. J. who made the following statement concerning the early years of his child's life:

> You see for the first two or three years of John's life he was very non-responsive and listless; it seemed like he just wanted to sleep twenty-two hours a day. We tried so hard to get him to do anything at all, that sometimes it seem, at least I felt like I was cracking up. Of course now there are infant stimulation programs and I'm sure that could have helped us then...instead of that, we got into a really expensive "patterning" program which we really regret now, but at the time anything that would help was better than just being able to do nothing at all.
>
> With a strong statement like this, it is not difficult to infer that this parent was experiencing high stress and anxiety at the time.

4b. Stress related to an excess of care-giving demands.

Generally the protocols are filled with references to the overwhelming influence that the dependent handicapped child has had on the parents and a good deal of this is connected to the physical/mental strain and life-restricting aspects of extensive care-giving demands. However, it is more difficult to track the parents' (especially the mother's) emotional reaction to this situation. Have they taken this situation in stride or has it caused them high stress and anxiety? Many of the protocols are peppered with self-statements like these:

"The whole process only increased the stress we already had."

"I got so tired and frazzled I forgot what it was like to have a clear head."

"You could get extremely upset about the whole thing if you let yourself."

"I feel like I never have any time for just myself."

"Every time I lift him I'm scared my back will go out again."

"I tried working part-time for a while but it was too much stress, too much to handle...even now I feel like I'm always doing a juggling act."

These kinds of statements in conjunction with the content to which the parents refer, and in the context they occurred, led the researcher to conclude that stress and anxiety constituted a major theme in the "life-world" of some but not all of the co-researchers, and therefore, a minor theme as defined in this thesis.

Theme V - Strong Effects of the Dependent Handicapped Child on Other Family Members (Minor)

Whereas the dependent handicapped child's effect on the mother's life course was predominant, the effects on the other family members appeared to depend on their degree of involvement with the child. For example, some fathers were almost equally involved in the day-to-day demands of looking after the child while others had largely an absentee role in favor of jobs or careers. Similarly the impact on the siblings depended on how much they assisted with care-giving demands or missed out on parent attention due to the need for the parents to expend greater time with the dependent handicapped child. It was this inconsistency, which of course also varied according to the presence of fathers and siblings, that resulted in this being considered a minor theme. Nevertheless, some major content related to the impact on fathers or siblings was apparent in all protocols of family units where they were present.

Variations of Theme V

5a. Effect on siblings.

Mrs. I. has provided a good description of how their dependent handicapped child has affected both the younger son and older daughter:

> It was quite a change when our younger son came along--because Ian had so many physical problems and hates noise to boot, we had to teach (younger son) to always be gentle and quiet around Ian. As a result (younger son) has turned out to be a fairly gentle and quiet boy and it's taken him a long time to learn how to fight for himself when he runs into problems at school and so forth. As for our older daughter, there is just no way I could cope with the situation if she wasn't around to help me out...as a result though, she has missed out on a lot of things other teenagers do because she has to stay at home with Ian. Also I don't want to think about all the meetings and parent things for her I've missed over the years. (Older daughter) is a great girl and so far she doesn't seem to resent the situation, but I know I often feel quite guilty about it.

5b. Effect on fathers.

It is difficult to make any overall statements about the fathers interviewed. This is because there

is a tremendous amount of variability in their expression depending on their involvement with the dependent child. One or two fathers even sounded genuinely surprised by the concerns expressed by their wives. It was discovered, however, that the fathers who were more involved in parenting were similar to their wives in terms of their expression of the themes as presented here.

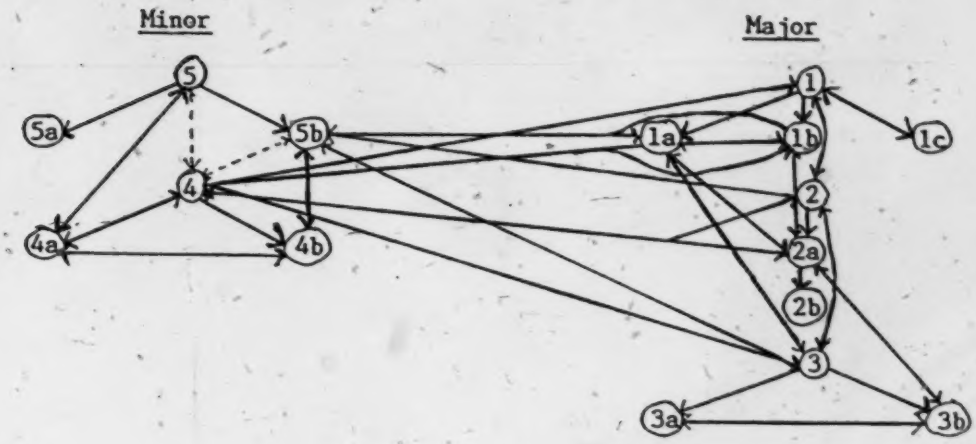
Summary and Interrelationships of the Themes

Although this section will also act as a theme summary, the main goal is to reveal how the various themes suggested in this chapter are interrelated. In terms of the six data analysis steps outlined by Colaizzi (1978), this section represents step 5 which suggests the need to "formulate an Exhaustive Description of the investigated phenomenon in as unequivocal a statement as possible" (Colaizzi, 1978, p. 59). Colaizzi goes on to explain that this requires a statement which entails both the content of the themes and how they relate to one another (p. 5). From the perspective of this researcher, because the themes have been reviewed in detail, there will be an emphasis on the interrelationships or integration of the themes. This is clearly an important aspect of the research because none of the themes actually stand alone. All in fact are strongly interrelated with one another. In

Table 1, on the next page, there has been provided a visual depiction of the theme interrelationship which represents the content of the discussion to follow.

Table 1

Diagram Of Integration Of Thematic Clusters



KEY

Themes	Variations of Theme
1. Predominant Influence on "life-world" of the mother.	1a - physical/mental strain 1b - life restrictions 1c - personal development
2. Strong Feelings about Type and Quality of Assistance Received.	2a - frustrations over not receiving proper services 2b - gratitude towards some professionals
3. Concern about Future of Dependent Handicapped Child.	3a - will child adapt to future situations? 3b - availability of services for the child in the future
4. Stress and anxiety.	4a - lack of proper help for child; parent or professional 4b - weight of care giving demands
5. Impact on other Family members.	5a - siblings 5b - fathers

The intent of establishing the interrelationships entailed in an exhaustive description is not to state that there are strict causal connections between the various themes, but to focus on the relationships between themes and theme variations as exhibited in the meaning of co-researcher description. For example, co-researchers expressing concern about future placements (3b) often justified their concern with reference to previous difficulties receiving assistance (2a) and thus the two theme variations are linked. It should be noted that a fair number of intuitive leaps or creative insights are required here to establish these links. Colaizzi (1978) notes how the phenomenological researcher is, "involved in that ineffable thing known as creative insight; he must leap from what his subjects say to what they mean". The use of such intuitive leaps or creative insights can be precarious, but it becomes less so as long as there is a grounding in the original protocols. Certainly this type of procedure is in keeping with the phenomenological research technique of using the researcher as a research instrument.

The themes and theme variations referred to in this section will be referenced to numbers or numbers and letters, as depicted in Table 1. It was discussed how the demands of the dependent handicapped child have

such a predominant and determining influence on the "life-world" of the mother (1). This was manifested largely in both the physical and mental strain (1a) and by the restrictions of other life activities (1b) caused by the tremendous workload of the care-giving demands. There were, however, a minority of mothers who were able to use their experience with their child as an avenue for personal development in related areas (1c). Here the relationship appeared somewhat reciprocal. The predominate influence of strain (1a) and life restrictions (1b) on the mother appeared to develop considerable stress and anxiety (4) in a majority of mothers. Often such stress and anxiety tends to escalate as the care-giving demands increase with the child's age. Perhaps because of the great needs of the child and the high impact on the parents, most parents looked for help from professionals and thus had strong feelings (2) about the assistance received. When they were frustrated (2a) in this search, perhaps this created further stress (4), and certainly did not reduce the strain on the mother (1a) or free any of her time (1b). It was suggested that high level of gratitude (2b) shown towards professionals who did help may partially relate to the contrast of this situation with those who were not helpful.

The concern about the future (3) was undoubtedly contributed to by strong skepticism (2) about what service might be provided in the future (3b) based on previous frustrations (2a). This concern about the future related to uncertainty about how their child would adapt (3a) to new future situation as well as the availability of services in the future (3b). There was also an indication that the concerns about the child's future (3) were related to increased stress and anxiety (4) in many cases. Also for some it was the effects of physical stress and strain (1a) (e.g. lifting) that were producing the necessity of seeking an alternative future (3) placement. In the case of other family members (5) it is probable that themes (2), (3) and (4) also had some strong effects on them, although it is difficult to know whether this in the case of siblings (5a) because they were not interviewed. Generally speaking, the fathers displayed more variation between one another in the content of what they said than the mothers. Perhaps this was because they varied so much in terms of their involvement with the dependent handicapped child. However, a number of them expressed particular concerns relative to theme (2) and also about their child's future (3). There were not many statements by fathers suggesting stress and anxiety (4)

in their lives related to the dependent child so this link is only tentative on the chart.

Chapter V

Discussion and Conclusions

In the previous chapter the five theme clusters were presented and their interrelationship reviewed. In this final chapter there remains the need to address a number of issues. These include: the limitations of the study, the effects of bracketing on the research process, the implications of the study for future research, as well as the conclusions and practical implications of the study.

Limitations of the Study

Several limitations of this study warrant attention at this point. These relate to the extrapolation of results, the representativeness of the co-researchers, the reliance on verbal self-reports, and difficulties in replicating the study.

Although the themes developed here are most likely representative of the co-researchers' experience, there is greater uncertainty when suggesting how much the findings are typical of the parents of dependent handicapped children as a whole. It was suggested earlier that the "life-world" of these co-researchers is a combination of their personal situations and how they interact through experience with the intersubjective meanings surrounding them in their society. It was discussed that these intersubjective meanings were socially constructed phenomena (e.g.,

art, laws, or trends in the treatment of the mentally handicapped). It would not be appropriate to extend the results of this study to the parents of the dependent handicapped operating in the context of significantly different intersubjective meanings than these co-researchers. Interacting with different surrounding intersubjective meanings would create different life-worlds. All of the co-researchers involved in this study were white and generally middle class residents of Alberta cities. It may therefore not be appropriate to extrapolate the findings of this study to the parents of the dependent handicapped in significantly different situations; for example, rural residents, distinct cultural groups, or even the residents of other cities with vastly different social agency structures.

At the same time, however, it may be questionable whether the co-researchers were representative of white, middle class, Alberta city, parents of dependent handicapped children living at home and enrolled in dependent handicapped school programs, even though the total numbers of parents meeting this criteria in the general population are not very large. For example, it may be that using only volunteers in this study resulted in the selection of a very specific type of parent as a co-researcher who in fact may be fairly

atypical. It should be noted that the researcher did take steps to prevent the selection of atypical co-researchers. For example, the Fort McMurray co-researchers, although volunteers, did receive some encouragement to participate from their child's teacher and in fact were parents less normally involved with school and community affairs. With regard to the Edmonton co-researchers, two early interviews were with highly active and vocal parents who would be quite interested in volunteering for this type of study. Subsequently, however, the researcher asked his contact in the parent association to see if some less active parents would be interested in volunteering, and the other Edmonton parents were in fact not the most active parents in the association. Thus although all parents were volunteers for this project, they were not necessarily the most active and involved parents in the community, who might normally be the first to volunteer for this type of research. Thus it is felt that the fact the co-researchers were volunteers may not have skewed the type of parents selected that significantly.

Another limitation of this thesis could be that it is based exclusively on verbal self-reports, and is therefore subject to the limitations of this methodology. In particular, as a product of "life-world" experience, the accuracy of verbal

self-reports can be distorted by such factors as the individual's self-awareness, ability to express oneself, and willingness to reveal personal life (Combs et al., 1976). Furthermore, the co-researchers' perceptions of, and reactions to the researcher during the interviews may have influenced the co-researchers' self-reports. It is hoped, however, that the personal motivation to participate in the study demonstrated by the co-researchers, and their desire to contribute to a greater understanding of the phenomenon, would control for the above possible limitations to some degree.

Finally, it should be noted that there could be some difficulty in replicating the results of this study. This is because the phenomenological nature of the study dictates the use of the researcher as a research instrument. Inevitable discrepancies in the intuiting process between researchers may produce some discrepancy in attempted replications. On the other hand, there are research procedures (e.g. bracketing) in place which enhance the defencibility of the knowledge claim. A large number of interviews, on more frequent occasions might have also increased the defencibility of the knowledge claim.

Effects of Bracketing Upon the Research

Earlier in this thesis there was included a quotation from the researcher suggesting life-situation

presuppositions which needed to be bracketed. The essence of the first bracketed presupposition was that it was felt that there would be a high degree of ongoing grief and sorrow in the parents' lives. Likely, this attitude also partially related to previous readings about the "grief process" (e.g. Kubler-Ross, 1969). There was an effort to contrast the presupposition against the parent description throughout. Two of the parents did refer to grief and sorrow and one had even read some of the related literature and felt it applied to her. At first there appeared to be a lot of grief and sorrow underlying what parents were saying. Gradually, however, it became apparent that there were few actual statements from the co-researchers relating to grief or sorrow overall and in fact there were a number of statements to indicate that it played a very little role in their lives. As one parent expressed it: "(Child's name) is a full member of our family and he has contributed as much or more than any of us, and we don't have the time to sit around and mope about things he can't do".

Another presupposition bracketed earlier had to do with parent/professional relationships. It was felt there might be communication difficulties between the two parties. As opposed to the presupposition involving grief and sorrow it became apparent that

almost all of the co-researchers were interested in talking about their relationships with professionals and a majority of these relationships had not been satisfactory from their perspective. In contrast, for example, reference to parent group organizations were quite sparse, especially considering that most co-researchers were nembers of parent organizations. Actually the role of professionals in the lives of co-researchers was much greater than expected in the researcher's presupposition about this. Moreover, it is such a concrete, real life theme, that it is very difficult to misinterpret when parents refer to it. A possibility for the parent/professional theme is that the co-researchers overstated it in the interviews in relationship to the true significance in their "life-world". This could have occurred because of their perception of the researcher as a professional or because relating experience about relationships with professionals can make a good story. However, the very noticeable emotional content in the stories the parents told about parent/professional contact, would suggest that these do indeed have much significance in their "life-world".

With regard to the other themes, the researcher had very few established preconceptions which could

have altered any theme's emergence, so it is assumed that researcher bias had very little influence.

Implications of the Study for Future Research

In this section there will be a contrast of the results of this study with the trends in previous research as outlined in the literature review. Stemming from this contrast will be an attempt to suggest future research direction that may be worthwhile.

First of all, if the theme clusters are compared to the results of the quantitative research reviewed earlier, it becomes apparent that there are some similarities and some differences to consider. It was suggested that a great deal of quantitative research deals with the existence of stress (Gallagher et al., 1983) in the parents of mentally handicapped children. Stress did reveal itself as a minor theme in the thesis, although it could be suggested that the quantitative research has given disproportional attention to it in view of the greater importance of the other themes. On the other hand, the phenomenological approach requires a clear connection between a theme or structure and actual statement by the co-researcher. It is possible that all parents interviewed did experience considerable stress, but simply did not express this in the interview. This

possibility would suggest that the presence of stress should be considered "major" as opposed to "minor". Certainly the situations described by all the co-researchers might be expected to create stress, although one cannot be sure that this was the case for all co-researchers since they did not all express their experiences with stress.

Some quantitative research (e.g., Bricklin, 1970; Dembo, 1969; Moos, 1976; Turnbull, 1978b) did study parent/professional relationships, and this would seem an appropriate area for continued study in view of the important, and often frustrating, role that the parent/professional relations have in the "life-world" of the parents. In contrast to the significant mention of parent/professional relationships, the co-researchers made absolutely no mention of concern about mainstreamed school programs as might have been predicted by Turnbull and Blacher-Dixon (1980), and quoted from Gallagher et. al., 1983 on page 30 of this thesis.

It may be of interest to compare the themes of this thesis to the main problems of the parents of the mentally retarded as listed by Robinson & Robinson (1976) in their description based on quantitative research results. Robinson & Robinson list the main difficulties faced by the parents as practical

problems, tendencies towards overprotection, effects on family integration, and effects on siblings (p. 424-431). Certainly some of the practical problems listed by Robinson & Robinson are reminiscent of problems expressed by the mothers who acted as co-researchers in ths thesis. There are also some similarities with regards to effects on siblings mentioned in both descriptions. Apart from this, however, their was very little similarity between the problems identified by Robinson & Robinson and the thesis themes.

In the literature review it was suggested that the extent of handicapping conditions or the number of care-giving demands are very important because of the co-relation with a variety of other factors (e.g. stress). In this thesis, there appeared to be a high degree of expressed parent experience also relating care-giving demands to a great variety of problems these parents faced. In view of the importance of day-to-day care-giving activities, further research on the nature and effects of care-giving activities might be very important.

Another distinct type of research reviewed in the literature review was the stage theory research. It was significant that not one co-researcher spoke about moving through a progression of stages of adaptation in

parenthood. Occasionally the researcher asked if the co-researchers felt they had changed in their attitude towards being the parent of a special needs child, over the years. Generally, the responses suggested that the parents did not feel they had changed significantly in relationship to their child. Therefore, the results of this thesis would tend to support the contentions of Allen and Affleck (1984) and others who have expressed skepticism about the applicability of the stage model to the parents of mentally handicapped children. Of course, as with the possible presence of stress, it is difficult to be sure that these parents have not gone through stages of adaptation. Perhaps they simply couldn't express or recall the stages they have gone through. Again we are dealing with the assumption of a close relationship between what people say and what they experience, which is an assumption of phenomenology. It was felt that the co-researchers were given adequate prompts to talk about change or stages to allow for the self-showing of such a theme had it been present in the experience.

Another important aspect of the stage theory research is that it suggests the parents experience a great deal of grief and sorrow in their adjustment process. As mentioned previously, few co-researchers spoke about grief or sorrow, and in contrast many spoke

about their total acceptance of the situation. Perhaps the fact that the youngest dependent handicapped child of the interviewed parents was five years of age, could mean that the parents had already worked through their grief by the time of the interviews. Although this is possible, none of the parents describe themselves as having more grief during the younger years of their child's life as might be predicted in stage theories.

The literature review also examined a few qualitative studies that relate to the parenting of mentally handicapped children. These included parent written self-reports (e.g., Pivato, 1984; Turnbull & Turnbull, 1978) and one phenomenological study (Wilgosh, 1985). The nature of the themes revealed in this thesis appear close to the content of the parent self-reports, in many cases. Certainly both emphasized the importance of the day-to-day concrete realities of parenting a mentally handicapped child, as opposed to underlying psychological emotions or processes. This would further point to the need for continued research focused on these concrete realities.

On the other hand, there were some overall differences between the themes here, and the parent self-reports (e.g., Pivato, 1984; Turnbull and Turnbull, 1978). Generally, although the parent experience as revealed by the thesis has many

optimistic and positive aspects, it appeared that the overall tone was somewhat more negative than in many edited parent self-reports, especially some of those provided by Pivato, 1984. This may suggest the need to further re-examine how much difficulty and frustration the parents of dependent handicapped children, in particular, are experiencing.

If the thematic results obtained here are compared to the Wilgosh (1985) study, there do appear to be a number of similarities. Of course, the narrower focus of the Wilgosh study resulted in greater specificity in the themes. However, similarities between the Wilgosh results and theme two (in this thesis) are apparent. Results in both cases may suggest the need for research related to parent involvement or frustration with professionals, agencies, or school programs in the community.

Conclusions and Practical Implications of the Study

In this section there will be an attempt to draw some conclusions about the findings of the thesis and suggest practical implications that may stem from such conclusions.

A most significant element in the themes, in terms of the implications, is the high number of concerns and difficulties the co-researchers have expressed. The co-researchers expressed many, and often severe

difficulties, with regard to the tremendous impact of looking after their child, relationships with professionals, and the future of the child. These parents appeared to require significant help in all three areas. Existing structures including parent organizations do not appear to be filling the gap. Perhaps the parents of younger children who have had the opportunity to benefit from recent directions in parent organization assistance are in a different situation, but the parents in this study certainly appeared to be expressing a need. The need is primarily for concrete practical help as opposed to therapeutic help in dealing with the problems. One certainly gained the impression that in-home aides, viable placement options, and liaison assistance with professionals would be greatly appreciated, while counselling assistance to help them deal with difficulties is, apparently, less needed. Even the stress and anxiety expressed by some parents seemed to be primarily a by-product of practical difficulties and thus it could be alleviated by addressing these.

Even though this study is about the parents of dependent handicapped children, it also has implications for professionals who work with these parents. It is self-evident that the value of assistance provided for these parents and children is

in many ways highly dependent upon a very positive parent/professional relationship. It is also possible that the extensive training of many professionals is being underutilized because of a specific lack of knowledge or skills when working with parents. Certainly the concerns with regard to parent/professional relationships expressed by the co-researchers would suggest that there is a great deal of room for improvement in these relationships. Perhaps continued investigation into the experience of the parents of mentally handicapped children may increase the knowledge base which professionals can refer to when dealing with parents. Also, a greater emphasis on parent/professional relationships in the training of professionals who deal with parents would be quite beneficial.

The thesis has also demonstrated the very central importance of the mother/child relationship in the case of dependent handicapped children. In order to achieve success in educational programs, this mother-child relationship needs to be effectively integrated with the child's educational needs. Again, the need for good parent/professional relationships is highlighted, because it is a prerequisite for effectively working with mothers, and all care-givers.

Finally, it may be appropriate to look at the title of this thesis because in many ways it contains the two main concepts which speak to the essence of the results, as well as the basic differences between how the co-researchers view themselves and how these parents are seen by many professionals. Professionals researching the parenting of mentally handicapped children are very frequently interested in the psychological process the parents go through. The most common psychological processes attributed to the parents, at least by the stage theorists, are grief and sorrow. The parents on the other hand, view their adjustment in terms of their interaction with the world. Thus they do well when they can get the assistance they need for their child. It could be suggested that they see their functioning as "co-constitutionally" (Valle and King, 1978, p. 8) related to their environment. Thus their emotions and feelings are a part of, and at one with what they experience, and one helps them by positively assisting with their experience, not by treating their emotions. When such parents continue to look to professionals for tangible assistance, and professionals continue to expect, or work on inner responses, perhaps it is not surprising that the parents become frustrated.

Instead of looking at the parents of mentally handicapped children in terms of adjustment to grief or sorrow, professionals may do better to think about what the actual lived-experience of these parents means. The results of this thesis would suggest that the lived-experience of the parents of dependent handicapped children can be summed up in one word: commitment. They are extremely committed to their child, have sacrificed a tremendous amount for the child, and they appear to run into difficulty when they can't fulfill their commitments to their child as they would wish to.

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APPENDIX I

Interview Consent Form

I,....., agree to participate in this parent-interview project conducted by Bruce Adams for his M.Ed. thesis, under supervision of Dr. L. Wilgosh and Dr. R. Sobsey, and to having the interview taped with the understanding that the tapes will not be identified in any way, to guarantee confidentiality of my name and personal opinions. Only key issues and concerns raised by parents will be summarized from the tapes and will not be associated, in any way, with individual parent identities.

.....

Signature (parents)

.....

Signature (Researcher)

.....

Date

APPENDIX II

Complete Explanation of Data Analysis Steps1

1. Read all of the subject's description, conventionally termed protocols, in order to acquire a feeling for them, a making sense out of them.

2. Return to each protocol and extract from them phrases or sentences that directly pertain to the investigated phenomenon; this is known as extracting significant statements. Several protocols may contain the same or nearly the same statements, thus repetitions can be eliminated. Furthermore, statements which refer to specific points can be transposed to more general formulation.

3. Try to spell out the meaning of each significant statement, known as formulating meanings. Particularly in this step is the phenomenological researcher engaged in something which cannot be precisely delineated, for here he is involved in that ineffable thing known as creative insight; he must leap from what his subjects say to what they mean. Ths is a precarious leap because, while moving beyond the protocol statements, the meanings he arrives at and formulates should never sever all connnection with the original protocols; his formulations must discover and illuminate those meanings hidden in the various contexts and horizons of

the investigated phenomenon which are announced in the original protocols. Contextual and horizonal meanings are given with the protocol but are not in it; so the researcher must go beyond what is given in the original data and at the same time, stay with it. He must not formulate meanings which have no connection with data.

4. Repeat the above for each protocol, and organize the aggregate formulated meanings into clusters of themes. The difficulties involved here are similar to those discussed in step 3, but more so since there is an attempt here to allow for the emergence of themes which are common to all of the subjects' protocols. Again, the ineffable consists of leaping from what is given in the meaning to themes given with them.

a) Refer these clusters of themes back to the original protocols in order to validate them. This can be achieved by asking whether there is anything contained in the original protocols that isn't accounted for in the clusters of themes, and whether the clusters of themes propose anything which isn't implied in the original protocols.

b) At this point, discrepancies may be noted among and/or between the various clusters; some themes may flatly contradict other ones. Here again the notion of approach comes to the fore because the researcher must rely upon his

tolerance for ambiguity: he must proceed with the solid conviction that what is logically inexplicable may be existentially real and valid. He must refuse the temptations for ignoring data or themes which don't fit, or of prematurely generating a theory which would merely conceptually-abstractly eliminate the discordance of his findings thus far.

5. The results of everything so far are integrated into an exhaustive description of the investigated topic, which includes an effort to formulate the exhaustive description of the investigated phenomenon in as unequivocal a statement of identification of its fundamental structure as possible.

6. A final validating step can be achieved by returning to each subject and asking the subject about the findings thus far. We can ask him, for example, "How do my descriptive results compare with your experiences? What aspects of your existence have I omitted?", etc. Any relevant new data that emerges from these interviews must be worked into the final product of the research.

[1]The data analysis steps are mostly quoted from Colaizzi; 1978 pg. 59 to 62, however, some references made to specific examples he uses have been omitted.